PARTNERS IN CANCER CARE:
BUILDING A QUALITY IMPROVEMENT COALITION

2002 – 2007 INFORMATION MANAGEMENT STRATEGIC PLAN

FINAL REPORT

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EXECUTIVE SUMMARY

The Cancer Services Implementation Committee's vision for cancer care is that "All Ontarians will have timely and equitable access to comprehensive and integrated quality cancer services". To achieve this vision, Cancer Care Ontario (CCO) is leading the creation of a comprehensive, integrated cancer program for Ontario. In June 2002, CCO initiated the development of an information management strategy to provide a plan for the acquisition and use of information and knowledge to improve cancer care.

This strategy has been designed to ensure a coalition of CCO and its partners can work together to build an integrated cancer system that ensures patients and their families, are cared for by a seamless network of services and professionals that is comprehensive and patient-centred.

To guide the strategy development efforts, a Cancer System Information Management Strategy Steering Committee was established. Membership included a broad cross-section of representatives from the cancer system. On September 25, 2002, CCO hosted a retreat, *Partners in Cancer Care: Building a Quality Improvement Coalition*. The retreat was attended by approximately 190 people representing a broad range of stakeholders and provided an ideal opportunity for a multitude of experts to participate in the process of developing the provincial cancer strategy.

To achieve the vision of timely and equitable access to comprehensive and integrated quality cancer services, five strategic Directions and nineteen initiatives are outlined in this strategy. The sequencing of implementations and investments reflects feedback from retreat participants and individual consultations, while recognizing the need to leverage existing system infrastructure and current initiatives. The estimated incremental cost of implementing this strategy is approximately $98 million over 4.5 years.

The five strategic Directions are as follows:

1. **Improving Access to Cancer Care**
   Lengthy waiting times for diagnosis and treatment can lead to sub-optimal clinical outcomes. Waits can occur in several areas including access to surgical procedures, radiation treatment, systemic therapy and diagnostic tests. The ability to manage and monitor wait times for these services varies. Initiatives will be undertaken to improve access to cancer care in Ontario, including the implementation of a comprehensive referral and wait list management system. A comprehensive approach will track each patient as they move between surgery, radiation and systemic therapy rather than managing these as independent events. It is only when a patient's interactions are managed across the continuum of cancer care that patients fully benefit from equitable access and increased quality of care.

2. **Enhancing Cancer System Performance**
   To facilitate strong system performance management, decision makers in the system need access to timely, accurate, and relevant system level data. However, a significant amount of detailed inter-institution information is not available. Initiatives within this Direction will improve data quality and support management's ability to enhance the performance of the cancer system. In pursuit of this direction, the Ministry of Health and Long Term Care has funded Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC) to support earlier recognition of pending constraints in the system, support development of mitigation strategies, identify best practices and increase efficiency in cancer service delivery. Furthermore, the Cancer Quality Council of Ontario has been established to monitor, assess and improve provincial performance of the cancer system.

3. **Enabling Optimal Clinical Decisions**
   All care programs should be designed to help care givers make the most appropriate clinical decisions and prevent clinical errors. There is strong evidence to suggest that Computerized Physician Order Entry (CPOE) of drug orders can significantly reduce error rates. This is especially true if the drug order entry system offers Clinical Decision Support (CDS) tools to provide physicians with clinical alerts at the time of order entry. The Program in Evidence-Based Care uses research results to influence practice by developing evidence-based clinical practice guidelines. Making guidelines readily available at the point of diagnosis and treatment enhances a physician's ability to make effective clinical decisions. Greater resources will be dedicated to developing guidelines, enhancing the quality and safety of systemic and radiation therapy and managing the health record as part of a larger, hospital/regional electronic health record. By providing tools to enable optimal clinical decisions, quality and consistency of cancer care will improve in Ontario.

4. **Building Research Capacity**
   In December 2000, the Ontario Ministry of Enterprise, Opportunity and Innovation established the Ontario Cancer Research Network (OCRN). The OCRN has a budget of $100 million to be invested over the next four years in cancer research infrastructure development in Ontario with an emphasis on translating new knowledge into clinical practice. Funding will focus on a cancer clinical trials infrastructure program, a cancer clinical trials information network, a tumour bank network and a cancer research projects fund. Initiatives in this strategy are designed to facilitate the building of cancer research capacity in line with the goals of OCRN. Ontario boasts a population of 11 million served by a single health system. This large population has the potential to create genomics databases on a scale that could revolutionize cancer care globally. Cooperation will be critical to the success of the OCRN and the achievement of this strategic direction.

5. **Facilitating Integrated Delivery of Cancer Care**
   Currently, delivery of cancer services is fragmented across health care organizations (host hospitals, other hospitals, regional cancer centres, other organizations and community-based providers). This fragmentation results in poorly coordinated patient care and costly duplication of administrative functions between providers. Integration at the care, management, information and technology levels will form the basis for a coordinated approach for cancer care across a multitude of providers and be a key enabler to achieve improved quality and access. The mechanism for improving the quality and efficiency of care for cancer patients will be the immediate establishment of Integrated Cancer Programs (ICP) in each region of Ontario. The resulting integration of cancer surgery and diagnostic services with the radiation and systemic therapy services traditionally provided by regional cancer centres will result in seamless coordinated care. In addition, a Cancer Coalition Intranet/Extranet will link all cancer system participants and serve as the conduit for disseminating cancer related information and facilitating the creation of new knowledge and standards for use by all providers.

This strategy outlines the information management directions for the entire cancer system. The inclusion of an initiative in this strategy does not imply that CCO will undertake its implementation. Indeed, CCO does not have the budget to lead every system implementation contemplated here and to achieve these strategic directions on its own. CCO will play a coordinating role through a Project Management Office and will work with all stakeholders to secure project funding to undertake these initiatives. The management of individual projects may come from hospitals, OCRN, other agencies or CCO itself. The success of this strategy depends on the goodwill and cooperation of all the partners involved in the Ontario cancer system. This is the heart of the coalition concept.

1. BACKGROUND & INTRODUCTION

The Cancer Services Implementation Committee's[1] vision for cancer care is that "**All Ontarians will have timely and equitable access to comprehensive and integrated quality cancer services**". To achieve this vision, Cancer Care Ontario (CCO) is leading the creation of a comprehensive, integrated cancer program for Ontario.

The integrated cancer program will support the following objectives:

- Quality care that supports the central role of the patients/clients and their families;
- Timely, equitable and appropriate access to comprehensive cancer services;
- A system of integrated and coordinated services that support a seamless care experience for the patient throughout the course of the disease;
- Clear accountability for the planning, provision and auditing of quality care, timely access to appropriate services, effective outcomes and performance improvements;
- Effective and efficient provision of services that makes the best use of human, financial, information and technological resources; and
- Conditions that attract and retain sufficient appropriately qualified care providers.

The initiatives outlined in this strategic plan have been developed with an understanding of the dynamic state of Ontario's cancer control system. The current cancer system is characterized by many governors and managers who oversee pieces of the system. It is fragmented and needs to be better coordinated to ensure patients have access to the range of services required. For example, CCO is responsible for approximately 75% of radiation services and 50% of systemic services. To move towards an integrated, high quality and responsive cancer system for Ontarians, CCO must work with its partners to build an integrated cancer system that ensures patients and their families, are cared for by a seamless, coordinated, network of services and professionals that is comprehensive and patient-centred.

Across the broader health system, resources for cancer services are scarce, demand for services is increasing, complexity of patient care is rising, and navigating the system is becoming more challenging. While it is positive news that patients are living longer with cancer due to new and complex therapies, this trend places an increasing burden on services for cancer patients.

To meet CCO's vision to "lessen the growing burden of cancer in Ontario by ensuring that Ontario residents have timely, equitable access to an integration system of coordinated and efficient programs in prevention, early detection, treatment (surgical, medical and radiation), supportive care, education and research", CCO has identified four corporate priorities for 2002/2003 and beyond:

- Accelerated integration of the cancer centres with the hospitals, through the development of Integrated Cancer Programs and ultimately Regional Cancer Programs;
- Establishment of a quality council, made up of experts, that will set standards, monitor cancer services and guide improvements to the cancer system;
- Improving the delivery and quality of surgical oncology; and
- Creation of a comprehensive information management program in Ontario to provide accessible information so that CCO can govern and manage more efficiently.

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[1] The Cancer Services Implementation Committee (CSIC), chaired by Dr. Alan Hudson, was struck in 2001 to make recommendations to improve integration of cancer services in Ontario resulting in improved quality of patient care and improved productivity and efficiency

To support this vision for cancer services, the Information Management (IM) Strategy will ensure that **all providers in the cancer system participate in the acquisition and use of information and knowledge to improve cancer care** through:

- Appropriate application of evidence based guidelines in all care settings to support consistent practice;
- Management decision-making at provincial, regional and local levels supported by the availability of relevant and consistent information and appropriate analytical tools;
- Integrated Health Records to support point-of-care access to relevant patient-related information while ensuring privacy and confidentiality;
- Monitoring of system performance at the provincial, regional and local levels to support expected outcomes and adherence to an accountability framework;
- Comprehensive datasets, with common data standards, to support practice reviews, peer comparisons, research and outcome evaluation; and
- Information technology infrastructure to support IM initiatives.

The coalition concept is the foundation for a coordinated approach for cancer care to improve quality and access. This strategy will be driven by new integration approaches, improved application of information management and a fundamental change in the roles and responsibilities of participants involved in cancer care. For example, the coalition will enable CCO to move away from its current service delivery role and allow other participants to deliver services in a more integrated and comprehensive manner. To ensure services are provided at a high level of quality, new incentive mechanisms will be established (i.e., contractual agreements that are tied to funding) to support achievement of the cancer vision for Ontario.

CCO recognizes the strategic importance of investing in information management and the direct relationship this has on cancer prevention, early detection, quality care and research outcomes. CCO has invested significant resources to develop key programs that have changed cancer in Ontario. Initiatives like the New Drug Funding Program, Program in Evidence Based Care, Ontario Breast Screening Program and the Ontario Clinical Oncology Group provide the building blocks for cancer care in the future.

In June 2002, CCO initiated the development of an information management strategy (see Appendix 1: Strategy Development Overview). To guide the strategy development efforts, a Cancer System Information Management Strategy Steering Committee (CSIMSSC) was established. Membership included a broad cross-section of representatives from the cancer system (see Appendix 2: CSIMSSC membership). An inventory of information resources at CCO was also conducted to support the strategy development (see Appendix 3: Information Management Resource Inventory).

By outlining a five-year strategy to support CCO and its partners to acquire and use information and knowledge to improve cancer care, this plan supports CCO's transition and the four corporate priorities. However, there are also other initiatives outside of the IM arena which also must be undertaken, and which are not specifically outlined in this document.

BACKGROUND & INTRODUCTION

The Information Management Strategy 2002-2007 will support and expand on initiatives to ensure that all providers in the cancer system can participate in the acquisition and use of information and knowledge to improve cancer care through the following five strategic Directions:

- Improving Access to Cancer Care;
- Enhancing Cancer System Performance;
- Enabling Optimal Clinical Decisions;
- Building Research Capacity; and
- Facilitating Integrated Delivery of Cancer Care.

The Information Management Strategy 2002-2007 details strategic directions, implementation priorities and illustrates what a comprehensive, integrated cancer program will look like.

2. STRATEGIC CONTEXT

The strategic directions and initiatives outlined in this plan will lay the informational foundation necessary to build an integrated cancer system that is seamless, coordinated, comprehensive and patient-centric. The following scenarios describe how such a system will look in five years, and the related initiatives in this plan that support these objectives.

Scenario One

While undergoing a routine breast screening exam, Mrs. Gupta was informed that she had a lump in her breast. Mrs. Gupta underwent further tests at the Regional Diagnostic Assessment Centre in order to determine the nature of the lump.

Ontario Breast Screening Program

Dr. Kendrick, her family doctor, was prompted of Mrs. Gupta's condition as the test results were automatically screened for positive results. Mrs. Gupta was called into Dr. Kendrick's office and was informed that she had breast cancer.

Pathology Information Management System

Dr. Kendrick then visited evidence-based care guidelines on the CCO website and determined that the current best practice for treating Mrs. Gupta was surgery to remove the tumour and the lymph nodes under her arm.

Program in Evidence Based Care

Continuing to use the website, Dr. Kendrick checked for the nearest hospital's availability for Mrs. Gupta's surgery. Dr. Kendrick found that the Integrated Cancer Program in Sudbury had the shortest waiting list for cancer surgery and, together with Mrs. Gupta, decided that the slightly longer travel to Sudbury was balanced off by the more rapid access to surgery.

Referral & Wait List Management

Following her operation, her surgeon told her that she would require radiation and chemotherapy treatments and would be eligible to participate in a clinical trial examining different protocols for adjuvant chemotherapy. Her surgeon referred her to a medical oncologist who told her more about the clinical trial. Mrs. Gupta used the Clinical Trials Network website to help her decide whether to participate in the trial. After reviewing the information, she decided to participate, knowing that this trial might benefit her and would help future cancer patients.

Clinical Trials Enrollment & Management System

Scenario Two

Mr. Davis was referred to the Kingston General Hospital to undergo surgery to remove a cancer of the colon. Upon his arrival at the centre, the regional EHR allowed Mr. Davis' surgical oncologist, Dr. Tao, to immediately retrieve the patient's clinical record along with practice guidelines tailored to his condition.

Regional EHR

Master Patient Index

Dr. Tao obtained the patient's agreement for participation in the tumour bank.

Tumour Bank

After surgery, Mr. Davis was referred to Dr. Guzman, a medical oncologist, for the chemotherapy portion of his treatment. Dr. Guzman electronically entered a treatment regimen for the patient, was immediately advised of the possible drug interactions, and was prompted to complete regimen-specific fields to support the claim for drug cost reimbursement from the New Drug Funding Program.

Computerized Physician Order Entry & Clinical Decision Support

New Drug Funding Program

At the completion of his treatment, Dr. Guzman referred Mr. Davis back to his family physician for ongoing follow-up care and noted that guidelines on the CCO website would assist the family physician in providing care.

Program in Evidence Based Care

Through the Internet, Dr. Guzman, was kept aware of supportive care services available to aid Mr. Davis.

Cancer Coalition Intranet/Extranet

3. STRATEGIC DIRECTIONS & INITIATIVES

Through the planning process, five main strategic directions have emerged to guide planning for the next five years. Each strategic direction encompasses a number of initiatives that will support the strategy.

3.1. IMPROVING ACCESS TO CANCER CARE

The Cancer Services Implementation Committee (CSIC) identified 'timely, equitable and appropriate access to comprehensive cancer services' as a criterion to be used to guide deliberations to meet the Committee's vision for cancer services. This sentiment was echoed at the recent Cancer Information Management Strategy Planning retreat "Partners in Cancer Care: Building a Quality Improvement Coalition" where delegates representing cancer stakeholders from around the province identified "Access Management for Cancer Services" as the top priority of the cancer system in Ontario (see Appendix 4: Retreat Summary).

As cancer services are provided by many care providers who represent a wide variety of professional groups in Ontario, coordinated access is critical to ensure that the right services are provided when and where they are needed. However, comprehensive information on access to cancer treatment is not available since current systems do not capture and aggregate information for all Ontario cancer patients. Furthermore, limited information related to the cancer system exists. This lack of information makes it difficult to manage referrals, track waiting times and ensure the availability of trained health professionals. The urgency of this situation is becoming more apparent as the incidence of cancer rises (three percent annually), treatment becomes more complex and as patients live longer with the disease resulting in an increased demand for services (seven percent annually).

Lengthy waiting times for diagnosis and treatment can lead to sub-optimal clinical outcomes. Waits can occur in several areas including, but not limited to, access to surgical procedures, radiation treatment, systemic therapy and diagnostic tests. The ability to manage and monitor wait times for these services varies:

- *Surgical Procedures*: While anecdotal evidence suggests that there are significant access problems for some surgical specialties in parts of the province, lack of concrete information and supporting systems makes arriving at definitive conclusions difficult.
- *Radiation Treatment*: Currently, waiting lists are relatively long and the rates of radiation treatment (percentage of incident cases treated with radiation therapy) are relatively low in comparison to other jurisdictions.
- *Systemic Therapy*: Anecdotal evidence suggests that there are growing problems in access to systemic therapy leading to significant wait times in several parts of the province.
- *Diagnostic Tests*: Evidence suggests that cancer patients are waiting in line for diagnostic tests (e.g. radiology, interventional diagnostic procedures) behind other patients with less life threatening or time sensitive ailments. Waiting times are compounded by slow communication of results.

A key challenge to efficient referral and wait list management is the need to address all treatment modalities rather than a single modality. For example, a comprehensive wait list tracking approach will track each patient as they move between surgery, radiation and systemic therapy rather than managing these as independent events. It is only when a patient's interactions are managed across the continuum of cancer care that patients and providers fully benefit from equitable access and increased quality of care. The approach should also measure and ensure equitable access to screening services, supportive and palliative care. Further opportunities to work with agencies like the Canadian Cancer Society to improve and track access to supportive care programs will be investigated.

All efforts will be made to utilize telehealth initiatives to improve access by capitalizing on communication and information technologies to deliver health care services over large and small distances. This can be especially constructive in rural areas as telehealth can be used to treat patients that would otherwise have to travel unreasonable distances to receive care.

The following initiatives will be undertaken to improve access to cancer care:

- Provincial Referral and Wait List Management, and
- Human Resource Planning.

3.1.1. Provincial Referral and Wait List Management

A province-wide referral and wait list management system will be implemented to support effective prioritizing of patients according to patient acuity and clinical need. This system will synthesize the necessary information (e.g., staging information) to determine patient priority and to analyze delays in diagnosis and treatment. A single system will be used by all providers in the province and every patient referred for treatment will be entered into the system. Like the Cardiac Care Network's[2] (CCN) computerized referral management and wait list tracking system that facilitates and monitors access to cardiac services, the system will leverage Internet technologies to provide timely statistics on access to services. It is important to note that referrals and wait lists will still be managed locally by providers.

The provincial referral and wait list management initiative will provide immediate benefits to Ontario's fragmented cancer care system. With the aid of a management system, providers will be able to prioritize cases based on the severity and type of cancer, manage wait lists and track demands for cancer services.

It will not be possible to implement this system all at once. A phasing approach will be carefully designed to maximize the value even when only partially implemented. Implementation is easier when the number of initial users is kept small, perceived utility of the system is high and frequency of use by each user is high. A variety of implementation approaches may be undertaken, including beginning with referrals for one modality (e.g. radiation), for one tumour site (e.g. breast), or starting in a focused geographic area (e.g. Kingston area).

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Provincial Referral and Wait List Management	Pilot plan complete	Pilot project implemented and evaluated	System implementation expanded	System implementation expanded	System implementation expanded

3.1.2. Human Resource Planning

Access to cancer services is adversely affected by the shortage of health care professionals. In particular, cancer care is experiencing a shortage of nurses, radiation therapists, oncologists, physicists, anesthetists and pathologists that is expected to worsen in coming years. To ensure effective human resource planning, demand and supply of services must be forecasted to allow system managers to project future human resource needs. However, detailed inter-institution information is not available to project future supply of specialized clinical professionals. With proper data, analysis and planning, Ontario can avoid potential wait list problems like the recent radiation crisis that resulted in the re-referral of patients to the United States.

The human resource planning initiative will:

- Track resources dedicated to providing cancer care to identify future needs and project future supply of clinical professionals;
- Use data on cancer incidence and prevalence from the Ontario Cancer Registry to predict probable demand for services;
- Provide data for the development of an overarching provincial strategy to support the training, recruitment and retention of a sufficient number of appropriately trained professionals to provide cancer services; and

[2] CCN is a partnership of health professionals, hospitals and government that focuses on ensuring appropriate and timely access to adult cardiac services by patients and their physicians.

– Identify potential gaps in the system before they become critical, while focusing on strategies to improve retention and productivity in key areas.

The collection and analysis of inter-institution data and development of statistical indicators for the supply and demand of health human resources likely would be outsourced to an agency (such as CIHI) well versed in tracking health human resources. The agency would publish annually its health human resources analyses and statistical indicators to aid in policy development and system planning.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Human Resource Planning		HR Planning outsource agreement signed; Reporting specifications determined	First annual report on supply and future needs published	Second annual report published	Third annual report published

3.2. ENHANCING CANCER SYSTEM PERFORMANCE

While health services research has revealed marked variability in practice patterns and outcomes between providers, institutions and geographic regions, a significant amount of detailed inter-institution information is not available. This variability and deficiency of information leaves system planners and decision makers without the clear evidence necessary to make well informed decisions around improving quality of care and access to cancer system resources. It is generally supported that having the right information available at the time of a decision increases the validity of the decision and contributes to a more successful outcome.

Focusing on quality, there is strong evidence to suggest that it is important to track clinical activity (i.e. volumes) by physicians and report back outcomes compared with provincial and regional peer groups. Some studies show widely varying clinical outcomes in different centres across the province. The best-known example is surgery of the pancreas where post-operative mortality rates were shown to vary by a factor of ten. Based upon the strong correlation that exists between poor outcomes and small volumes, a strategy that provided surgeons and hospitals with performance benchmarks that compared their surgical outcomes to those of others in the province was implemented. Anecdotal evidence suggests that since the dissemination of the surgery data, surgery rates have declined in low volume centres.

To facilitate strong system performance management, decision makers in the system need access to timely, accurate, and relevant system level data. Through the strategy development process, several areas have been identified as lacking the ability to provide system level performance data including provincial information on cancer outcomes, clinical and pathologic stage, screening, diagnosis, location of treatment, compliance with best practice guidelines, costs, and human resource needs. To support the enhancement of cancer system performance, appropriate analytical skills to support interpretation of data, improved data integration infrastructure and relevant applications and databases are required (see Appendix 5: Information Infrastructure).

This direction and the related initiatives provide the necessary foundation for the establishment of comprehensive and consistent funding approaches for cancer services in Ontario. Through the collection and use of timely and accurate activity, outcome, complexity and financial data, well-defined envelopes of funds that are protected for cancer services, and an allocation methodology that incorporates volume, complexity and quality factors can be established for cancer services, including radiation, cancer surgery and systemic therapy. While these funding approaches would provide the necessary financial incentives to ensure cancer programs are a recognized priority, the funding envelopes will also influence where services are provided thus impacting on quality outcomes and patient satisfaction. For example, larger hospitals might be volume-funded for high complexity surgeries, localized to a few centres while simpler, low risk surgeries are provided closer to home. This funding approach will also provide incentives to support timely and accurate submission of cancer related information necessary for operational planning and research purposes.

The following initiatives will be undertaken to enhance cancer system performance:

- Quality Council;
- Enhance Analytical Capability to Enable Outcomes Tracking and Develop Funding Models;
- Data Integration Infrastructure;
- Pathology Information Management System (PIMS);
- Database and Data Sources;
- Cancer Staging Information;
- Screening Tracking; and
- Enhancement to the Ontario Cancer Registry.

3.2.1. Quality Council

In September 2002, the Minister of Health and Long-Term Care announced the establishment of the Cancer Quality Council of Ontario (CQCO) to "monitor, assess and improve clinical and health system performance of all cancer services in Ontario. These services include health promotion and disease prevention, screening and early detection, primary care, diagnosis, treatment, rehabilitation, home/community care, palliative and supportive care." To meet this mandate, the CQCO requires system level data be defined, collected and reported in a suitable fashion and tangible improvement opportunities to be identified and acted upon. A Secretariat will be established to implement and manage CQCO projects.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Quality Council	Establish Secretariat	Ongoing CQCO analysis & reporting			

3.2.2. Enhance Analytical Capability to Enable Outcomes Tracking and Develop Funding Models

In recent years, health services research has identified variability in practice patterns and outcomes between providers, institutions and geographic regions. Although the causes of this variability are not completely understood, a number of sources of sub-optimal outcomes have been identified including:

- Clinical errors, resulting in sub-optimal therapy that inadvertently harms the patient;
- Lack of application of current evidence-based treatment;
- Low patient volumes making it difficult to maintain a standard of practice consistent with optimal outcomes; and
- Access problems that lead to selection of sub-optimal therapies or clinically relevant treatment delays.

As awareness of these factors has emerged in recent years, it has become clear that major improvements in patient outcomes are possible through the implementation of strategies designed to mitigate these factors. An excellent example is the dramatic variability in postoperative mortality seen across Ontario for pancreatic cancer. A strategy that provided surgeons and hospitals with performance benchmarks that compared their surgical outcomes to those of others in the province has resulted in major shifts in practice patterns. Anecdotal evidence suggests that many surgeons who were performing small numbers of procedures are now opting to refer patients to larger volume centres. This approach will be expanded to include many other aspects of cancer treatment.

A major thrust being launched is to replicate the experience with pancreatic cancer in other disease sites. Increasing analytical capability will result in province wide programs to improve patient care including:

- Approaches to reporting performance against provincial benchmarks back to providers to enable them to identify opportunities for modifying practice to improve outcomes;
- Development of a comprehensive and consistent funding approach for cancer services that includes an allocation methodology that incorporates volume, complexity and quality factors (e.g. surgical oncology funding model);
- Establishing minimum standards necessary for surgeons, physicians and hospitals to achieve optimal clinical results (e.g. minimal annual volume levels necessary for good outcomes);
- Developing a patient safety culture to enable reporting of adverse events and changes to the system to prevent similar events from occurring in the future; and
- Offering education programs targeted at identified quality improvement opportunities.

Monitoring outcomes, setting standards and targeting areas for quality improvement have stimulated interest in provincial databases that include clinical information such as tumour site, stage, treatment received and outcome measures. Capturing this data accurately and in a timely fashion is a major objective of the D-TRACC initiatives outlined below.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Enhancing Analytical Capability	Enhanced analytical capability to enable outcomes tracking and development of appropriate funding approaches				

3.2.3. D-TRACC

In 2000, the Ministry of Health and Long-Term Care initiated the Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC) project to implement a flexible and cost effective system to provide comprehensive planning and management information for cancer treatment activity, quality and accessibility (see Appendix 6: D-TRACC Overview). The MOHLTC has given CCO the mandate for ongoing operation of the D-TRACC system. D-TRACC will support the earlier recognition of pending constraints in the system and support development of mitigation strategies, identification of best practices and increase efficiency in cancer service delivery. D-TRACC will leverage existing initiatives to the greatest extent possible (e.g. Smart Systems for Health). The following sub-projects have been defined:

3.2.3.1 Data Integration Infrastructure

The establishment of truly integrated cancer programs will require a data integration infrastructure for the efficient, reliable and confidential sharing of information. The infrastructure will leverage two key components: Interface Engines and a provincial Master Patient Index (MPI).

To facilitate cancer care, information must move between different systems, both within and between organizations. The Interface Engine serves as the connector to enable the sharing of data between hospital applications. This is accomplished by securely filtering, translating and routing data from one system to another, thus enabling applications to share information.

While each institution uniquely identifies each patient, a unique identifier across the health system does not exist. This results in the inability to cross-reference activity occurring at different institutions and reduces the ability to share and integrate information. The MPI will be used to uniquely identify patients across the system, independent of where the care is received while protecting the privacy and confidentiality of patient information.

This level of data integration will be required for the deterministic linkage of data required for the comprehensive treatment and outcomes database (D-TRACC) and for supporting the research agenda. It is also essential for integrating cancer systems with hospital Electronic Health Records and other clinical systems.

Cancer services in Northern Ontario are currently characterized by a lack of integration between various providers, delayed detection of disease due to access issues, and less than optimal care. It is proposed that Northern Ontario be the pilot site for developing the data integration infrastructure (See Appendix 7: North Project 1: Establish a Cancer Information Infrastructure). Once the infrastructure has been developed and refined, it will be introduced into other regions in the province. These same tools can then be used to address the data integration needs of other provincial and regional programs unrelated to cancer.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
DTRACC - Data Integration Infrastructure	Data Integration Strategy Complete; MPI/IE selected	3 additional Integrated Cancer Programs indexed to the MPI; 2 Northern Integrated Cancer Programs and 10 Northern hospitals indexed to the MPI	8 additional Integrated Cancer Programs and 12 Northern hospitals indexed to the MPI	16 additional hopitals and 14 Northern hospitals indexed to the MPI	20 additional hospitals indexed to the MPI

3.2.3.2 Pathology Information Management System (PIMS)

The Pathology Information Management System (PIMS) has been piloted successfully in three laboratories in Ontario with pathology reports sent electronically into a centralized database. The system will be expanded to include all pathology laboratories in Ontario (see Appendix 8: List of Pathology Laboratories for PIMS Implementation) and will utilize the Smart Systems for Health network infrastructure. PIMS will be the foundation data source for the D-TRACC project by providing initial identification of a cancer patient. Once a patient is identified in the system, opportunities become available to provide system level management information as well as disseminate practice guidelines and clinical trial protocols to front line practitioners.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
DTRACC - PIMS	Privacy impact assessment complete; 5 lab sites added	25 sites added via CCO interface engine; existing sites converted to CCO interface engine	26 sites added via CCO interface engine	25 sites added via CCO interface engine	

3.2.3.3 Database and Data Sources

To enable the use of detailed system level management data, D-TRACC data sources will be combined into a centralized database. This database will combine data from the PIMS project, the Ontario Cancer Registry, Princess Margaret Hospital/University Health Network, CIHI inpatient and ambulatory data and several other provincial and national databases. One of the main components of this database will be that all sources will be linked deterministically through the provincial Master Patient Index (see initiative 3.2.3.1). This deterministic link ensures that the combination of a patient's information from the data sources is correct, allowing D-TRACC to be used for timely identification of cancer and enrollment in clinical trials. Together, these data sources will provide an effective source of management information which enables decision makers to make informed decision around cancer system planning, capacity and referrals. Linking of data sources will require careful attention to the privacy and confidentiality interests of patients. Issues such as patient consent, protection of patient identity, compliance with legislative requirements and secure data management will be addressed to maintain the public trust.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
DTRACC - Database and Data Sources	Database and Functional design complete; Wait time reporting requirements defined	Data repository complete; Deterministic linkage mechanism based on OHN complete	Interfaces to existing data sources complete (ALR, PMH, CIHI DAD); CIHI NACRS data source complete	OHIP Billing data source complete; Standard reports complete	Deterministic linkage with Vital Statistics data source complete

3.2.3.4 Cancer Staging Information

The electronic capture of clinical and pathological stage information is important for interpreting outcomes, planning, cancer surveillance, making treatment decisions and monitoring the applicability of guidelines. Accessing clinical stage information will have a profound effect on the quality of care delivered in the cancer system.

Comprehensive staging information requires the collection of pathological and clinical stage. A majority of pathological staging information is collected via the PIMS system. Clinical stage information may be best captured through refinement of existing systems supported by the data integration infrastructure. This system will be rolled out to include all healthcare facilities where cancer diagnosis and treatment occurs. This includes all providers of cancer surgery, radiation and systemic therapy. Standards will be developed to determine how often stage information is collected. A data quality unit will be created to ensure the ongoing data validity. In some situations, it may be necessary to put regional data coordinators in place to facilitate data collection.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
DTRACC - Cancer Staging Information		Data Quality (Staging) Unit established	50% documentation of stage at diagnosis;	100% documentation of stage at diagnosis; 25% documentation of stage during clinical care	100% documentation of stage during clinical care

3.2.3.5 Screening Tracking

A screening tracking mechanism will identify and track individuals who access provincial screening programs. This mechanism will monitor the quality of screening, facilitate appropriate follow up, provide routine reminders about the next required screening test and evaluate outcomes. Implementing a screening tracking mechanism requires significant cooperation of the large number of primary physicians and others providing screening services. By utilizing the data sources of the D-TRACC project, the creation of a screening tracking mechanism will allow screening outcomes to be analyzed on a regional and provincial basis, facilitating proper management and development of screening programs.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
DTRACC - Screening Tracking			Mechanism to link screening data to OCR and DTRACC complete		

3.2.4 Enhancement to the Ontario Cancer Registry

The Ontario Cancer Registry (OCR) is a computerized database of information tracking all incidence and mortality of cancer cases in Ontario. All new cases of cancer are registered (except non-melanoma skin cancer). Data in the OCR are used to conduct epidemiological and health care utilization studies and evaluate the efficacy of screening programs. Typically, studies that rely on data in the OCR use patient data that is passively collected. Upgrades to the OCR, such as improving database matching mechanisms or collecting more timely data, will enable more active use of the OCR. Over time, there may also be a need to expand data elements collected or initiate surveys (e.g., periodic population-based survey of risk factor exposure and involvement in preventive interventions).

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Enhancement to Ontario Cancer Registry			OCRIS upgrade & enhancement		

3.3. ENABLING OPTIMAL CLINICAL DECISIONS

All care programs should be designed to help care givers make the most appropriate clinical decisions and prevent clinical errors. Rather than assigning blame to a particular caregiver, the emphasis should be placed on improving the clinical process that resulted in a less appropriate decision or allowed for an error to occur.

The Program in Evidence-Based Care (PEBC) uses research results to influence practice by developing evidence-based clinical practice guidelines. Although the PEBC has approximately 80 guidelines available on its website, the degree to which these are followed is unclear. Making guidelines readily available at the point of diagnosis and treatment enhances a physician's ability to make an effective clinical decision. Furthermore, tracking and reporting practice patterns relative to guidelines back to physicians would substantially improve awareness of guidelines and quality of care.

Currently, approximately half of all systemic therapy orders in the province are entered by physicians directly into computer systems (mostly at CCO regional cancer centres). There is strong evidence to suggest that Computerized Physician Order Entry (CPOE) of drug orders can significantly reduce error rates. This is especially true if the drug order entry system offers Clinical Decision Support (CDS) tools to provide physicians with clinical alerts at the time of order entry. Once Clinical Decision Support mechanisms have been implemented for cancer, the learnings and infrastructure can be leveraged for use in health systems outside of cancer with only marginal additional investments. With greater resources dedicated to developing guidelines and implementing clinical decision support rules, the emphasis on quality and consistent care supported by evidence can be enhanced in areas where guidelines already exist and extended to other areas of cancer care.

The following initiatives will be undertaken to support optimal clinical decisions:

- Expand Program in Evidence Based Care;
- Enhancing the Quality and Safety of Systemic Therapy;
- Specialized Systems for Radiation; and
- Linkages with Regional Electronic Health Records.

3.3.1. Expand Program in Evidence Based Care

With an annual budget of $800,000, the PEBC uses research results to influence practice by developing evidence-based clinical practice guidelines. Teams made up of health care providers, community representatives and researchers select and review the best and most relevant studies, synthesize relevant research information, obtain input from specialists and make recommendations for optimizing cancer care. The groups also develop evidence summaries on clinical topics where there is insufficient evidence to develop a practice guideline. Guidelines and summaries are disseminated to clinicians and planners and are accessible over the Internet. The New Drug Funding Program reimburses hospitals and cancer centres for chemotherapy treatments prescribed according to evidence-based guidelines developed by PEBC.

The PEBC budget will be increased to:

- Continue to add additional guidelines, especially involving the use of radiotherapy, supportive care and screening;
- Develop CDS rules that alert physicians when guidelines apply to their patients at the time of order entry with an initial focus on systemic therapy cases;
- Assess stage specific treatment practice provincially to determine consistency of practice with evidence;
- Communicate to physicians and hospitals the extent to which their practice patterns are consistent with guidelines; and
- Track changes in consistency with evidence as it changes over time with various interventions.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Expansion of Program in Evidence Based Care	Ongoing program expansion				

3.3.2. Enhancing the Quality and Safety of Systemic Therapy

Currently, although RCCs and Princess Margaret Hospital collect detailed data on systemic therapy, there is limited province-wide information on diagnosis, location of treatment, compliance with best practice guidelines, outcomes, stage and costs. Furthermore, CIHI reporting requirements in Ontario do not require abstracts for outpatient systemic therapy. See Appendix 9 for a list of Ontario hospitals providing chemotherapy.

CCO will establish functional requirements for systemic therapy systems, set standards and certify various vendors that are compliant with these requirements. The key to this process will be meeting the functional requirements. Choosing certain vendors may make meeting requirements easier but it is meeting the requirements that is key, regardless of vendor. If hospitals choose to use a systemic therapy management system that is CCO certified, CCO will pay the costs of system implementation and maintenance. Funds will be provided upon the achievement of set goals such as physician use benchmarks, electronic data transfer to CCO and regional expansion. If a system is selected that does not meet functional standards, the hospital alone will be responsible for the costs of system implementation and maintenance. Furthermore, the hospital remains responsible for providing the real-time data feeds in a format specified by CCO.

This approach will improve the quality of systemic therapy by ensuring access to the following information management technologies

- **Computerized Physician Order Entry (CPOE)** to reduce adverse events and facilitate better data collection on the use of systemic therapy throughout the province;
- **Clinical Decision Support** system to provide physicians with suggestions on how to improve diagnosis and treatment to be consistent with evidence-based guidelines; and
- **Change management mechanisms** to motivate changes in behaviour needed to achieve desired outcomes and promote necessary change.

A strong focus must be placed on ensuring that physicians interact with these systems directly, rather than through an intermediary. CDS will not be effective if the physician is not present to receive information provided by the CDS system. Less than 50% of chemotherapy orders are entered through CPOE today. The goal is to increase this to 100% across the province in five years.

Near real-time reporting of chemotherapy ordering practice to CCO through the interface infrastructure is an important objective. Both D-TRACC and the Cancer Registry will become much more useful if data collection is current, complete and automatic. Comprehensive outcomes monitoring will support the clinical quality improvement initiatives outlined elsewhere in this strategy.

To ensure required information is received in a timely and accurate manner, electronic receipt of data submission to CCO will be tied to reimbursement. For example, linking the New Drug Funding Program reporting to payment will not only support monitoring of the program but also eliminate slow and inefficient manual paper invoicing.

Integration with hospital Electronic Health Record (EHR) systems is essential and will leverage the data integration infrastructure. Data must be transferred between the systemic therapy system and other clinical systems in the hospital to ensure that the EHR contains all clinical record information on the patient. Likewise, the systemic therapy system must have access to clinical record information such as lab results and drug orders to enable CDS to have optimal clinical impact. This strategy will provide the funds to hospitals to achieve this integration.

Providing quality cancer care to patients living in the remote communities of Northern Ontario is a challenge. The large distances patients need to travel to access care create emotional and financial hardships for patients and their families. An oncology information system is to be implemented in the North in partnership with healthcare providers in the region that builds on existing investments in health systems and network infrastructure. This system will see the delivery of chemotherapy CPOE rolled out to the approximately 40 peripheral and outreach cancer centres across Northern Ontario (see Appendix 7: North Project 2: Enhance the Quality and Safety of Systemic Therapy).

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Enhancing the Quality and Safety of Systemic Therapy	System requirements analysis complete; CCO certified systems defined; 2 Northern ICPs complete	3 additional ICPs complete; CDS rules added; 10 Northern hospitals complete;	4 additional ICPs complete; CDS rules added;12 additional Northern hospitals complete;	4 additional ICPs complete; CDS rules added;14 additional Northern hospitals complete;	12 additional hospitals complete; CDS rules added. Total sites implemented: 61

3.3.3. Specialized Systems for Radiation

Cancer centres require specialized systems for managing radiation therapy services. Standardizing on certified radiation systems will result in economies of scale that include cost efficiencies, consolidated reporting opportunities and improved quality of care. To this end, CCO will establish functional requirements and set standards for radiation systems and a certification plan similar to the systemic therapy plan detailed above. CCO will certify radiation treatment systems that meet established functional requirements and fund hospitals that choose to implement these systems. Functional requirements for certification of radiation treatments systems will be developed by surveying providers of radiation treatment to identify key needs and preferred providers. To improve care delivery, the radiation systems will be integrated with the host hospital systems (e.g. PACS, laboratory, and pharmacy). Finally, we will centrally consolidate radiation specific information from all radiation treatment programs, including Princess Margaret Hospital, to support system planning and comprehensive outcome analysis.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Specialized Systems for Radiation	System requirements analysis complete; CCO certified systems defined	CCO certified systems implemented in 3 Radiation Treatment Centres	CCO certified systems implemented in 3 additional Radiation Treatment Centres	CCO certified systems implemented in 2 additional Radiation Treatment Centres	

3.3.4. Linkages with Regional Electronic Health Records (EHR)

To facilitate integration and improve quality, host hospital EHRs will be extended to serve cancer programs as well. The cancer record will be managed as part of a larger electronic record containing the patient's clinical history. Where there is an overlap in functionality between host hospital EHR systems and the CCO certified radiation and systemic therapy systems, the host hospital system will be used to facilitate maximum integration of patient information. However, if the host hospital EHR system cannot support CCO mandated functionality or CCO required data submissions for surveillance and funding purposes, a CCO certified system must be used to receive funding through CCO. Implementation of such systems will be phased in over time.

Currently, the majority of cancer clinical activity in Ontario is supported by paper and manual processes. There is limited access to information systems for direct patient care and clinical systems are not integrated. As a result, significant delays in clinical care occur and patient safety is threatened when time is taken to look for and transfer paper-based information. Furthermore, significant costs are incurred with redundant processes and repeated tests.

There are several reasons for implementing a regional EHR rather than a provincial or disease specific EHR. First, different vendors across the province increase the difficulty of implementing a provincial EHR. Second, most of the care provided to an individual patient is likely to occur in the same region. Third, all clinical information on each patient should be electronic, and not limited to cancer information. As more hospitals move towards digital imaging and PACS, opportunities to leverage the electronic exchange of images for both treatment and research purposes will be realized. The regional EHRs will facilitate the timely sharing and efficient distribution of images by leveraging Internet technologies and data transmission standards/protocols.

CCO will require access to real time data from host hospital systems and will therefore implement and maintain an interface infrastructure to effect the required submissions. Host hospitals will ensure that their vendors provide the necessary HL7 compliant interface capability required to effect these interfaces. Registration functions will be transferred from the currently utilized OPIS system to host hospital registration systems.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Linkages with Regional Electronic Health Records	Each hospital responsible for their own local schedule				

3.4. BUILDING RESEARCH CAPACITY

Ontario has an international reputation for its cancer research that includes basic, clinical, translational and health services research. Research in Ontario is conducted by investigators affiliated with a wide range of organisations, including universities, affiliated teaching hospitals, co-operative clinical trials groups, PMH/OCI, CCO, ICES and private industry.

In December 2000, the Ontario Ministry of Enterprise, Opportunity and Innovation established the Ontario Cancer Research Network (OCRN). The OCRN has a budget of $100 million to be invested over the next four years for cancer research infrastructure development in Ontario with an emphasis on translating new knowledge into clinical practice. Funding will focus on four key areas:

- A **Cancer Clinical Trials Infrastructure Program** that will provide funds to increase the number of patients enrolled in trials and to enhance the quality and consistency of the cancer trials process.
- A Cancer **Clinical Trials Information Network** that will inform both patients and physicians about cancer clinical trials being conducted in Ontario. A database of Ontario clinical trials accessed through a variety of communication and support tools will facilitate the clinical trials process and exchange of trials information.
- A **Tumour Bank Network** that will coordinate cancer tissue procurement, storage and distribution to qualified investigators. The Bank will develop an extensive genetic, biological and clinical database on all registered tumour types. By making high quality tissues and accompanying data sets more readily available to cancer researchers, the Tumour Bank will identify the genetic determinants of cancer causation and response to therapy, leading to diagnosis and therapy that is tailored to the needs of each individual patient. This comprehensive program in tumour genetics will accelerate the identification of new drug targets and treatments and foster biomedical enterprise.
- A **Cancer Research Projects Fund** that will support a broad spectrum of translational research projects in Ontario, through research grants focused on finding and testing new cancer treatments.

The success of the OCRN depends on developing partnerships and cooperation among providers and investigators throughout the entire cancer care community. Much of the information infrastructure contemplated in this strategy for clinical and management purposes is also essential for a successful research informatics program. There is a tremendous opportunity to build information structures that will meet the needs of both service delivery and research simultaneously.

Both the clinical trials and tumour bank agendas will rely on accurate and complete clinical information for reporting and analysis. The integration architecture contemplated in other sections of this strategy will prove ideal for facilitating research data collection and linkage on a scale never before contemplated. Ontario boasts a population of 11 million served by a single health system. This large population has the potential to create genomics databases on a scale that could revolutionize cancer care globally.

The following initiatives will be undertaken to build research capacity:

- Clinical Trials Enrollment and Coordination;
- Clinical Trials Management IM Infrastructure; and
- Clinical and Genetic Databases to Support Tumour Banking.

3.4.1. Clinical Trials Enrollment and Coordination

Clinical trials are a cornerstone to ongoing improvement of care. Currently, enrollment in clinical trials is a complex undertaking due to the number of trials conducted across the province, the variety of sponsors and the relative independence of each trial and investigator.

To facilitate and speed an increase in clinical trial enrollment, clinical trial infrastructure of uniform quality will be established in each region of Ontario. Trial availability and eligibility criteria will be integrated into routine care to facilitate the enrollment process. Internet based technologies will likely be leveraged to improve timely dissemination of the infrastructure.

Projects such as D-TRACC, PIMS and collection of staging information will result in databases with a wealth of information that can prospectively identify trial-eligible patients. These systems will rely on electronic data transfer in near real time to allow possible recruits to be identified at the time care is initiated. The same clinical decision support systems that identify the clinical guidelines applicable to a patient can also be used to identify clinical trials protocols that might be suitable. In some situations, it may be necessary to put regional data coordinators in place to facilitate trials enrollment. The data integration infrastructure (section 3.2.3.1.) will also facilitate the population of clinical trials databases for study management. As these clinical and management systems are planned and implemented, OCRN requirements will be incorporated into the design.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Clinical Trials Enrollment & Coordination	Establish trial coordinators and deploy		Implement trial coordinators		

3.4.2. Clinical Trials Management IM Infrastructure

A clinical trials infrastructure program will be developed to maximize the efficiency of conducting clinical trials. Currently, many organizations have developed their own electronic or paper systems to manage trials. These processes are inefficient, resulting in increased cost and lost opportunities for Ontario patients and researchers.

The process of conducting a clinical trial continues to depend predominantly on very labour intensive manual processes. Data feeds from interface engines will be used wherever possible to speed data collection, improve accuracy and facilitate more rapid completion of trials. IM infrastructure to facilitate trials accounting and tracking of patient progression through experimental protocols will be implemented in centres across the province.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Clinical Trials Management IM Infrastructure		Select and deploy trials infrastructure		Extend trials infrastructure	

3.4.3. Clinical and Genetic Databases to Support Tumour Banking

Ontario has a unique opportunity to establish a single standard data structure to capture tumour information for the entire cancer population. Given the large number of human genes and the multifactorial nature of genetic expression, the analysis of large numbers of patients is required to correlate genotype with clinical behaviour. This will require the development of a fully-linked comprehensive database for cancer research that includes clinical records, the genetic bio-file and linkage to tissue samples in a tumour bank.

Provincial coordination is essential to develop this single database and the information infrastructure to support it. Once the relationships between genotype and clinical behaviour are understood, they can be used in clinical practice to tailor care for individual patients. To accomplish this, clinicians will need access to the patient's genetic bio-file to optimize their treatment program. Enabling a link between the tumour bank and clinical databases is necessary for translation of research results into clinical practice.

CCO will act as a custodian for identified patient information linked to the tumour bank. This information will be stripped of patient identifiers and transferred to OCRN for research purposes. CCO will continue to collect relevant clinical information for linkage to tumour bank specimens to ensure that complete clinical profiles are collected for patients participating in the research program. The data interface infrastructure will permit reliable and continuous collection of clinical information securely linked to tumour bank specimens into the future.

The successful implementation of this research program will require careful attention to the privacy and confidentiality interests of patients. Issues such as patient consent, protection of patient identity, compliance with legislative requirements and secure data management will be addressed to maintain the public trust.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Clinical & Genetic Databases to Support Tumour Banking	Initiate development of clinical databases		Continue development of clinical databases		

3.5. FACILITATING INTEGRATED DELIVERY OF CANCER CARE

Currently, delivery of cancer services is fragmented across health care organizations (host hospitals, other hospitals, regional cancer centres, other organizations and community-based providers). This fragmentation results in poorly coordinated patient care and costly duplication of administrative functions between providers. Integration at the care, management, information and technology levels will form the basis for a coordinated approach for cancer care across a multitude of providers and be a key enabler to achieve improved quality and access.

Facilitating the integrated delivery of cancer care will require improved application of information management and fundamental changes in the roles and responsibilities of participants involved in cancer.

The following initiatives will be undertaken to facilitate integrated delivery of cancer care:

- CCO – Hospital Agreements; and
- Cancer Coalition Intranet/Extranet.

3.5.1. CCO – Hospital Agreements

The establishment of an Integrated Cancer Program (ICP) in each region, and the resulting integration of cancer surgery and diagnostic services with the radiation and systemic therapy services traditionally provided by regional cancer centres, is critical to improving the quality and efficiency of care for cancer patients.

Beginning immediately in two regions and building on the work and experience of Grand River RCC and Toronto Sunnybrook RCC, CCO will work with the host hospital of each regional cancer centre to establish agreements to form ICPs that function as an integral part of the hospital's operations. The ICP Agreements will detail the responsibilities of both the host hospital and of CCO and will outline key performance requirements including service delivery, information sharing and adherence to provincial standards for access and quality. These performance measures will be the basis for funding of the ICP by CCO.

To support a rational approach to increasing resources for care, maintaining appropriate funding, and ensuring appropriate clinical outcomes, volume-complexity funding formulas for cancer services (including surgery and systemic therapy) will be developed (See section 3.2.2).

Some aspects of the ICP will be uniform across the province and other dimensions may vary depending on local circumstances. In all cases, access to high quality patient care will be the critical determining factor in settling the terms of the ICP agreements. Over time, Regional Cancer Programs (RCP) also will be developed in each region.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
CCO-Hospital Agreements	Volume-Complexity funding formulas complete for Radiation and Chemotherapy; NEORCC and HRCC to Host Hospital ICP contracts signed	Volume-Complexity funding formulas complete for Surgery; Remaining ICP contracts signed	RCP agreements developed		

3.5.2. Cancer Coalition Intranet/Extranet

A Cancer Coalition Intranet/Extranet will serve as the integrative mechanism for linking cancer system participants and act as an agent for promoting system level change. This initiative will be funded through CCO and will serve as the conduit for both leveraging and disseminating cancer related information and facilitating the creation of new knowledge and standards for use by all providers. The Coalition Intranet/Extranet will leverage current intranet resources and technologies (e.g., knowledge management tools, guidelines, protocols, new research and findings) of partners and serve as a means to effectively link these resources together. The primary goal of the Coalition Intranet/Extranet is to provide a mechanism to connect Coalition partners together in order to share and disseminate information and knowledge resulting in improved care through changes in practice, better decision-making, and gains in efficiency and productivity. For example, the Coalition Intranet would be used to disseminate guidelines, document availability of supportive care programs and services and provide updates on educational programs.

Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Cancer Coalition Intranet/Extranet	Intranet/Extranet Strategy complete		Increase content and use		

4. IMPLEMENTATION PRIORITIES 2002 - 2007

To achieve the vision of timely and equitable access to comprehensive and integrated quality cancer services, five strategic directions and nineteen initiatives have been articulated above. Through the strategic planning process, initial draft directions and initiatives were reviewed and assessed by a number of key participants in the cancer system (see Appendix 4: Retreat Summary). The sequencing of implementations and investments reflects feedback from the retreat participants and consultations, while leveraging existing system infrastructure and current initiatives.

Once this strategy is endorsed by the coalition partners, CCO will take the lead in establishing a Project Management Office (PMO) to coordinate the implementation of this strategy. Formal project plans and project teams will be established for each initiative and detailed planning will commence with the full participation of user organizations.

This strategy outlines the information management directions for the entire cancer system. The inclusion of a project in this strategy does not imply that CCO will undertake its implementation. Indeed, CCO does not have the budget to lead every system implementation contemplated here. CCO will play a coordinating role through the PMO, and will work with all stakeholders to secure project funding to undertake these initiatives. The management of individual projects may come from hospitals, OCRN, other agencies or CCO itself. The success of these initiatives depends on the goodwill and cooperation of all the partners involved in the Ontario cancer system. This is the heart of the coalition concept.

The strategic initiatives outlined in this strategy are at the conceptual stage, so the scope, timelines and costing outlined in the following pages are meant to describe directional intent. Significant additional work with involved stakeholders is required before detailed project timelines and budgets can be established. The estimates included herein should be treated as preliminary projections that will be refined as the scope of each project develops better definition.

The estimated incremental cost of implementing this strategy is approximately $98 million over 4.5 years[3]. This estimate does not include:

- The cost to implement regional EHRs across the province;
- Costs to integrate regional cancer centre operations into host hospitals; or
- Ongoing operating costs (which are assumed to be borne by CCO and hospitals that own the systems).

This $98 million is incremental to the $25 million CCO spends on IM annually. There are a variety of sources for this funding outlined in Appendix 10. Approximately one third of the funding is already in place.

As a result of the broad, directional nature of this document, it will require periodic updates to remain relevant. A significant strategic review will occur annually to recalibrate the strategy to changing technology and system needs.

Successful implementation of the strategy is dependent on the availability of skilled and experienced people. Significant work will be undertaken to identify resource skillsets required and ensure timely recruitment.

Excellent communication is the key success factor in uniting this coalition to achieve this strategic effort together. The PMO will issue quarterly status reports to communicate progress in implementing this strategy

[3] All costs are based on 2002 dollars.

to all stakeholders. More detailed information will be provided regularly to organizations directly involved in implementing individual projects. Opportunities for dialogue and evaluation of progress will facilitate fine-tuning of the strategy for optimal performance.

Table 1 details the five strategic directions and nineteen initiatives that constitute the 2002-2007 IM Strategic Plan as well as the projected timelines for each initiative and the approach to implementation across the province.

Table 1 – Implementation Priorities 2002-2007

Strategic Direction	Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Improving Access to Cancer Care	**Provincial Referral and Wait List Management**	Pilot plan complete	Pilot project implemented and evaluated	System implementation expanded	System implementation expanded	System implementation expanded
	Human Resource Planning		HR Planning outsource agreement signed; Reporting specifications determined	First annual report on supply and future needs published	Second annual report published	Third annual report published
Enhancing Cancer System Performance	**Quality Council**	Establish Secretariat	Ongoing CQCO analysis & reporting			
	Enhancing Analytical Capability	Enhanced analytical capability to enable outcomes tracking and development of appropriate funding approaches				
	DTRACC - Data Integration Infrastructure	Data Integration Strategy Complete; MPI/IE selected	3 additional Integrated Cancer Programs indexed to the MPI; 2 Northern Integrated Cancer Programs and 10 Northern hospitals indexed to the MPI	8 additional Integrated Cancer Programs and 12 Northern hospitals indexed to the MPI	16 additional hopitals and 14 Northern hospitals indexed to the MPI	20 additional hospitals indexed to the MPI
	DTRACC - PIMS	Privacy impact assessment complete; 5 lab sites added	25 sites added via CCO interface engine; existing sites converted to CCO interface engine	26 sites added via CCO interface engine	25 sites added via CCO interface engine	
	DTRACC - Database and Data Sources	Database and Functional design complete; Wait time reporting requirements defined	Data repository complete; Deterministic linkage mechanism based on OHN complete	Interfaces to existing data sources complete (ALR, PMH, CIHI DAD); CIHI NACRS data source complete	OHIP Billing data source complete; Standard reports complete	Deterministic linkage with Vital Statistics data source complete
	DTRACC - Cancer Staging Information		Data Quality (Staging) Unit established	50% documentation of stage at diagnosis;	100% documentation of stage at diagnosis; 25% documentation of stage during clinical care	100% documentation of stage during clinical care
	DTRACC - Screening Tracking			Mechanism to link screening data to OCR and DTRACC complete		
	Enhancement to Ontario Cancer Registry			OCRIS upgrade & enhancement		

Table 1 – Implementation Priorities 2002-2007 (Continued)

Strategic Direction	Initiative	Year 1 2002-03 (6m)	Year 2 2003-04	Year 3 2004-05	Year 4 2005-06	Year 5 2006-07
Enabling Optimal Clinical Decisions	**Expand Program in Evidence Based Care**	Ongoing program expansion				
	Enhancing the Quality and Safety of Systemic Therapy	System requirements analysis complete; CCO certified systems defined; 2 Northern ICPs complete	3 additional ICPs complete; CDS rules added; 10 Northern hospitals complete;	4 additional ICPs complete; CDS rules added;12 additional Northern hospitals complete;	4 additional ICPs complete; CDS rules added;14 additional Northern hospitals complete;	12 additional hospitals complete; CDS rules added. Total sites implemented: 61
	Specialized Systems for Radiation	System requirements analysis complete; CCO certified systems defined	CCO certified systems implemented in 3 Radiation Treatment Centres	CCO certified systems implemented in 3 additional Radiation Treatment Centres	CCO certified systems implemented in 2 additional Radiation Treatment Centres	
	Linkages with Regional Electronic Health Records	Each hospital responsible for their own local schedule				
Building Research Capacity	**Clinical Trials Enrollment & Coordination**	Establish trial coordinators and deploy	Implement trial coordinators			
	Clinical Trials Management IM Infrastructure		Select and deploy trials infrastructure	Extend trials infrastructure		
	Clinical & Genetic Databases to Support Tumour Banking	Initiate development of clinical databases	Continue development of clinical databases			
Facilitating Integrated Delivery of Cancer Care	**CCO-Hospital Agreements**	Volume-Complexity funding formulas complete for Radiation and Chemotherapy; NEORCC and HRCC to Host Hospital ICP contracts signed	Volume-Complexity funding formulas complete for Surgery; Remaining ICP contracts signed	RCP agreements developed		
	Cancer Coalition Intranet/Extranet	Intranet/Extranet Strategy complete	Increase content and use			

The estimated incremental cost of implementing this strategy is $98 million over 4.5 years. Table 2 summarizes implementation costs by strategic direction.

Table 2: Strategic Direction Implementation Costs

Strategic Direction	Initiative Budget (Millions)
Improving Access to Cancer Care	$10
Enhancing Cancer System Performance	$29
Enabling Optimal Clinical Decisions	$28
Building Research Capacity	$20
Facilitating Integrated Delivery of Cancer Care	$4
Project Management	$7
Total	$98

As CCO does not have the budget to lead every system implementation and initiative, CCO will play a coordinating role and will work with stakeholders to secure project funding to undertake these initiatives. Approximately one third of the funding is already in place. Sources to fund the IM initiatives are outlined in Appendix 10 and include:

- D-TRACC Initiative ($17.5 million initial allocation from MOHLTC)
- CCO Funding (~ $20 million)
- Ontario Cancer Research Network
- Northern Ontario Heritage Fund
- Canada Health Infoway Inc.
- Ministry of Health and Long Term Care

APPENDICES

Appendix 1: Strategy Development Overview

The Cancer Services Implementation Committee (CSIC) was struck in response to public concerns about waiting lists for radiation therapy and the ability of the current system to meet the growing need for cancer services of all kinds. The focus of the Committee was to recommend ways to improve the integration of cancer services at the local and regional levels, the quality of patient care, and the productivity and efficiency in the cancer service component of the Ontario health system. In December, 2001 *the Report of the Cancer Services Implementation Committee* was presented to The Honourable Tony Clement, Minister of Health and Long-Term Care.

Following up on the recommendations of CSIC, CCO has developed a comprehensive IM strategic plan for all cancer services across the province. This plan supports the recommendations made by CSIC and provides a roadmap for the cancer system over the next five years.

In order to guide the process of strategy development, a Cancer System Information Management Strategy Steering Committee (CSIMSSC) was created. Membership included a broad cross-section of representatives from the cancer care system. (See Appendix 2 for committee membership.) The CSIMSSC met five times over the course of strategic development and provided input to guide the planning process.

The planning methodology used to develop the strategy is described below:

Assess Current Environment

In the first phase of the strategic planning process, a substantial environmental scan was carried out. The scan included interviews with over 120 cancer stakeholders, numerous site visits to cancer service providers and a comprehensive data collection exercise.

Choice of interviewees was based on the need to ensure broad representation from Ontario's cancer system. Those interviewed included representatives of regional cancer centres, host hospitals, and selected community hospitals providing cancer care. Interviews were also carried out with representatives of the Ministry of Health and Long Term Care, Cancer Care Ontario, the Ontario Cancer Research Network, professional groups, agencies responsible for other parts of the health system and a variety of other organizations. Interviewees included a number of CEOs, CIOs, line managers, clinicians, expert advisors, researchers and government officials (see Attachment 1.1 for a full list.)

The data collection exercise included a substantive review of existing CCO IM infrastructure. This included a systems inventory of all regional cancer centres and a detailed analysis of information management systems at provincial office. A comprehensive IM spending exercise identified the current amount being spent to maintain and improve CCO's information management capabilities.

Results from the environmental scan provided the base required to develop key strategic options.

Develop Key Strategic Options:

In the second phase of the strategic planning process, assumptions and criteria were developed and reviewed by the CSIMSSC. The input from the interview process and environmental scan was compiled and organized into two broad categories:

1. A set of proposed Cancer System Priorities; and
2. A set of proposed Cancer Information Management Initiatives to support the Cancer System Priorities.

It was clear that all priorities and initiatives were important, however decisions had to be made about the sequencing and speed of implementation. While CCO was seen as taking a leadership role in implementing the strategic plan, it was recognized that all players involved in the delivery of cancer care and cancer-related services would need to be fully engaged in both developing and implementing the cancer strategy. Hence, on September 25th, CCO hosted a retreat titled "Partners in Cancer Care: Building a Quality Improvement Coalition". The retreat was attended by approximately 190 people and provided an ideal opportunity for a broad range of partners in cancer care to participate in the process of developing the provincial cancer IM strategy.

To aid in prioritizing, the retreat was designed to give participants the opportunity to rank the urgency of priorities and initiatives and provide input into the development of the cancer IM strategy. Feedback from the retreat was used to create the IM strategy which was pre-circulated to retreat participants prior to finalizing.

Deliver Information Management Strategy

In the final phase of strategic development, multiple drafts of the strategy were created and distributed broadly within the cancer system for review and comment. The resulting IM strategic plan has incorporated the thoughts of a broad range of stakeholders.

APPENDIX 1

Attachment 1.1: Consultation List

- Hamilton Regional Cancer Centre onsite visit
- Kingston Regional Cancer Centre onsite visit
- Toronto Sunnybrook Regional Cancer Centre onsite visit
- Northern Hospital and Centre Representatives
- Regional Cancer Centre CEOs
- Regional Cancer Centre CIOs
- Committee - CCO Executive Management Team
- Committee - Cancer Quality Council of Ontario
- Matthew Anderson - (CIO, UHN)
- Bob Bell (VP & COO, UHN/PMH)
- Netanis Boger (MOHLTC)
- Melissa Brouwers (PEBC, CCO)
- Adalsteinn Brown (Dept. of Health Administration, U of T)
- Tom Closson (CEO, University Health Network)
- Tony Dagnone (CEO, London Health Sciences Centre)
- Michael Decter (CIHI)
- Roger Deeley (Head Research Division, CCO)
- Dennis Egan (CEO, Grand River Hospital)
- Bill Evans (EVP System Therapy Program Leader & Director, Cost Evaluation & Quality Improvement, CCO)
- Margaret Fitch (Supportive Care, CCO)
- Debbie Fitzsimmons (DS-Web, CCO)
- Cathy Fraser (IT Team Leader, DRCC/Lakeridge)
- Kevin Glasgow (Cardiac Care Network)
- Mary Goh (CCO)
- Dan Gordon (CEO, Praxia)
- Carol Herbert (OCRIS, CCO)
- Martin Hodgkinson (D-TRACC Consultant)
- Glenn Holder (OMA)
- Eric Holowaty (Ontario Cancer Registry, CCO)
- Ozgur Huner (UHN)
- Vicki Kaminiski (CEO, Sudbury Regional Hospital) & Timmins Representative (Outreach Role)
- Rimy Kaur (UHN)
- Jack B. Kitts (CEO, The Ottawa Hospital)
- Donna Kline (VP Public Affairs, CCO)
- Renee Laforet (MOHLTC)
- Andreas Laupacis (President & CEO, ICES)
- Peggy Leatt (Chair, Health Administration, Chapel Hill)
- Les Levin (MOHLTC)
- Verna Mai (CCO)
- Linda Lizotte-Macpherson (President and CEO, Canada Health Infoway)
- Bill MacKillop (Radiation Oncologist/Epidemiologist Health Services Research KRCC)
- Frank Markel (Executive Director, JPPC)

- Murray Martin (CEO, Hamilton Health Sciences Corporation)
- Terry Michaelson (Director, Technical Systems, PMH)
- Debbie Miliken (New Drug Funding Program, CCO)
- Sandy Nuttall (MOHLTC)
- David Pattenden (CEO, OMA)
- Chris Paige (VP Research, UHN)
- Bob Phillips (Ontario Cancer Research Network)
- Peeter Poldre (Director Education, CCO)
- Doug Ramsay (MOHLTC)
- Sylvia Shedden (Ontario Breast Screening Program, CCO)
- Colin Smith (UHN)
- Terry Sullivan (VP Preventative Oncology, CCO)
- Lorelle Taylor (MOHLTC)
- Tony Whitton (Radiation Oncology Coordinator, CCO)
- Brent Zanke (CCO)

Appendix 2: Cancer System Information Management Strategy Steering Committee Membership

- Margaret Mottershead (Chair)
- Robert Bell – UHN
- Randy Bissett – NEORCC
- Stewart Boecker – UHN
- George Browman - HRCC
- Ian Brunskill – CCO
- Michael Guerriere – Courtyard Group
- Alan Hudson – CCO
- Glen Kearns – Grand River Hospital
- Donna Kline CCO
- Sam Marafioti – Sunnybrook & Women's
- Sandy Nuttall – MOHLTC
- Carol Sawka – TSRCC
- Terry Sullivan – CCO

Appendix 3: Information Management Resource Inventory

An inventory of information resources at Cancer Care Ontario was collected as part of the strategy development process. The process for collecting this inventory included an environmental scan of the applications, hardware and network infrastructure in place in each of the Regional Cancer Centres and Provincial Office as well as the major applications used in each of the Host Hospitals. A detailed financial spreadsheet was distributed to the RCCs for collection of data on information management expenditures in 2001/02. In addition, interviews were conducted with key contacts for each of the major Provincial Office information resources.

The results of the Information Management Resource Inventory are documented in this appendix.

Appendix 3a provides a summary of the key information management resources in use or in development at Cancer Care Ontario. The IM resources described in this section are those that are either centrally managed or have been centrally initiated by Provincial Office. In some cases, the IM resource is a system, in other cases it is a program that is supported by one or more databases. Each IM resource is described in terms of the functionality it provides, the data that is captured and stored, the users of the resource and how the information is used.

Appendix 3b provides a comparative summary of the IM resources that are used in each of the Regional Cancer Centres. This information was collected as part of the environmental scan.

Appendix 3c provides a high level summary of the major applications in use in each of the nine host hospitals. This information was also collected as part of the environmental scan.

Appendix 3d provides key financial analysis based on the 2001/02 IM expenditure data that were collected.

Appendix 3a: Summary of the Key CCO Information Management Resources

Ontario Cancer Registry

Description:	The Ontario Cancer Registry (OCR) is a computerized database of information on all Ontario residents who have been newly diagnosed with cancer ("incidence") or who have died of cancer ("mortality"). OCR provides a snapshot of cancer status in Ontario helping to assess the burden of cancer and identify patterns in the occurrence and control of the disease. It is essential for planning programs and resources. All new cases of cancer are registered, except non-melanoma skin cancer. Cancer is not a reportable disease in Ontario, therefore, submission of data to OCR is voluntary.
Functionality:	OCR is used for the following purposes: • Surveillance (examining trends in cancer incidence and mortality rates and analyzing geographic variation in cancer rates across the province); • Dissemination of data to the Canadian Cancer Registry at Statistics Canada (annually), the North American Association of Central Cancer Registries (annually) & the International Agency for Research on Cancer; • Population-based epidemiological studies; • Research studies; • Linking data to other databases such as OBSP; • Reporting cancer statistics to the public on an annual basis.
Database Contents:	The data contained in OCR includes: CIHI Hospital Discharge Abstracts; Pathology Reports (paper), Pathology Data (PIMS); Registered Person Database (MOHLTC); Registrar General (Mortality Data); Chemo/Radiation Clinic visits from RCCs & PMH; Data from Other Provincial Registries.
Usage:	As of August 2002, a total of 24 people have direct access to the Ontario Cancer Registry Information System. The 24 people represent the following organizations: • Public Health Branch of the Ministry of Health (receives data for its community health information system); • International Agency for Research on Cancer; • CIHI; • Breast Familial Registry; • Colon Familial Registry; • CCO - OCR staff.

Pathology Information Management System

Description:	The Pathology Information Management System (PIMS) is used to connect pathology laboratories to the Ontario Cancer Registry in order to electronically collect and code pathology reports for inclusion in OCR.
Functionality:	PIMS accepts an electronic data feed from the pathology system, automatically codes the pathology report and then transmits the report and the coded pathology data to CCO for inclusion in OCR.
Database Contents:	The data in the PIMS database includes: Pathology reports and coded pathology data.
Usage:	As of August 2002, there are four pathology labs using PIMS: Gamma Dynacare, Rouge Valley, Lakeridge Health, Cambridge Memorial Hospital. CCO Registry staff use the PIMS database to extract and verify coded pathology reports. Users of the information also include all groups identified under OCR.

Oncology Patient Information System (OPIS/OPIS2000)

Description:	OPIS is an Oracle-based Oncology Clinical Information system developed by CCO staff starting in 1989. It is used by the Regional Cancer Centres to manage the scheduling, treatment and follow-up of cancer patients seen at the RCCs. OPIS 2000 is the systemic therapy order entry module developed by CCO staff in 1995. OPIS 2000 was designed using a graphical user interface in order to encourage more physicians to use the OPIS system.
Functionality:	OPIS/OPIS 2000 provides the following functionality: Patient Registration; Disease Registration; Scheduling; Treatment Planning; Code Capture; Chart Tracking, Transcription, Radiation Therapy Wait Times, Patient Follow-Up, Order Entry, Pharmacy, Automatic Dose Calculation, Commercial drug database and Optional E-mail Alerts. OPIS 2000 automatically prompts a physician to enroll a patient in the New Drug Funding Program if certain conditions are met. On a monthly basis, data feeds from OPIS go to OCR to report patient incidence data and to ALR to report NHPIP coded workload data. The ALR data is used for Wait Time Reporting and for reimbursement under the New Drug Funding Program.
Database Contents:	The OPIS database includes the following data: Patient demographics and encounters, initial consults and multi-disciplinary clinics, scheduling information, record of radiation treatment, transcribed reports, follow-up visits, minor related cancer surgery; disease registration, treatment codes, systemic therapy orders, systemic therapy treatment data and adverse reaction data for decision support.
Usage:	There are between 120-180 users in each of the large RCCs (TSRCC, LRCC, KRCC, HRCC, ORCC) and between 40-60 users in each of the small RCCs (NEORCC, NWORCC, WRCC). OPIS/OPIS 2000 is used by virtually all clinical and administrative staff in the RCCs.

Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC)

Description:	The goal of the D-TRACC initiative is to create a flexible and cost effective database that will capture and link data from a variety of sources in order to provide comprehensive and consistent planning and management information on cancer treatment activity, quality and accessibility. Phase 1, Systems Assessment and Consultation and Phase 2, System Design and Functional Planning are complete.
Functionality:	The output information will be used for various reports and analysis such as Provincial Activity Reports, Wait Time Analysis Reports, Quality of Treatment Analysis, Outcome Analysis by Site, Stage and Treatment Type and Constraint Analysis.
Database Contents:	The DTRACC database is intended to include Initial Diagnosis data, Radiation Treatment data, Systemic Treatment data, Surgical Treatment data, Mortality data and Supportive care data. Proposed data sources include: OHIP Billing database, Hospital systems, CIHI DAD/NACRS, RCC OPIS/IMPAC, CCO ALR, Pathology Labs, PIMS, CCACs IMS, Registrar General, Provincial/Regional Staging Unit.

IMPAC (Multi-Access)

Description:	IMPAC is an integrated oncology information system. IMPAC was selected through an RFP process based on comprehensiveness and suitability of their products and services, industry specific expertise and proven application integration capability. IMPAC's product, Multi-ACCESS, is currently being implemented as a pilot project in NEORCC and NWORCC. The primary goals of the IMPAC project is to make all relevant patient treatment information available electronically during the patient encounter, to replace the current OPIS/OPIS2000 system and to explore process improvement opportunities.
Functionality:	Multi-Access will be used to manage the scheduling, treatment and follow-up of cancer patients seen at the RCCs. The following modules are being implemented at NEORCC and NWORCC: Patient Registration, Scheduling, Diagnosis, Treatment Planning, View Station, Pharmacy, Systemic Therapy Order Entry, Physician Notes, Utilization Reporting, Chart Tracking, Quality Checklist, PDA/Tablet Integration, Outlook Integration and Mail Messaging. Data feeds will go to the Registry to report patient incidence data; to ALR to report NHPIP coded workload including visits, procedures, radiation treatments and systemic therapy treatments.
Database Contents:	Following implementation, the database will include: patient registration data, disease data, chart tracking, scheduling information, detection and diagnosis information, treatment and follow-up information, clinical chart, systemic therapy orders, radiation therapy images, transcribed notes.
Usage:	Multi-ACCESS is being implemented as a pilot project in NEORCC and NWORCC and will be used by clinical and administrative staff at these centres. Following the pilot implementations, the project will be evaluated to determine if Multi-Access should be rolled out more broadly.

Program in Evidence Based Care (PEBC)

Description:	The purpose of PEBC is to facilitate best cancer practice by developing evidence based care treatment guidelines (CPGs).
Functionality:	CPGs are used to assist patients and health care providers in making appropriate decisions about cancer care. The PEBC Web-site contains information about the mandate of the program as well as all approved guidelines organized by disease site.
Database Contents:	Evidence based care treatment guidelines (CPGs) for patients, families, and health care providers. There are currently 80 CPGs available and 108 are in progress.
Usage:	PEBC are used by Ontario physicians, cancer patients and their families. Other provinces and countries have adopted some guidelines and have used them as a starting point in developing their own treatment guidelines.

DS-Web

Description:	The purpose of DS-Web is to organize and allow access to Activity Level Reporting (ALR) data and other types of management information available at CCO. It is created as a multidimensional cube access to information and was evolved from a one- dimensional Excel spreadsheet format.
Functionality:	The information is distributed to the RCCs for reference use and is used as a management information tool.
Database Contents:	As of August 2002, the following data are available through DS-Web: ALR data, New Drug data, Physician case data. In the future, the following data will be available: Registry data, Utilization Workload, GR data, HR & Systemic data.
Usage:	There are currently 85 registered users from CCO Provincial Office and from the RCCs.

New Drug Funding Program (NDFP)

Description:	NDFP was created by Cancer Care Ontario in 1995 to reimburse hospitals and RCCs for expensive new chemotherapy agents that are not covered by hospital budgets. In 2001/02, $50 million will be funded through NDFP. Currently NDFP funds 14 chemotherapy agents with 28 indications. The Managed Systemic Therapy database (MST) is used by CCO to manage eligibility and reimbursement.
Functionality:	A Policy Advisory Committee recommends to Cancer Care Ontario the drugs and the eligibility criteria for funding. The MST data is input to the CCO Financial System and used to reimburse hospitals and RCCs for eligible chemotherapy agents.
Database Contents:	The data for MST comes from 3 different sources: 1. Paper based eligibility forms submitted by hospitals and entered manually into MST; 2. Electronic eligibility forms entered in Chemo trac (Chemo trac is in the majority of the 80 hospitals that participate in NDFP); 3. OPIS 2000 (an electronic eligibility form is integrated into OPIS 2000)
Usage:	80 hospitals participate in NDFP. NDFP requires participating hospitals whose claims are more than $10,000 per year to use of Chemo trac for electronic submission. NDFP staff (2 FTEs) use MST; CCO Finance staff use MST data for reimbursement. DS-Web is used as the reporting tool for NDFP information.

Ontario Breast Screening Program (OBSP)

Description:	The purpose of the Ontario Breast Screening Program is to reduce mortality from breast cancer by delivering to women 50 years of age and over a comprehensive, organized, and evaluated breast cancer screening program that is sensitive to women's needs, builds on health promotion behaviours, and fosters partnerships with interested groups in the community.
Functionality:	OBSP uses the "Integrated Client Management System" (ICMS) as their application and database. ICMS was developed in-house in 1991 using Oracle and Powerbuilder. It is accessible via the Internet to all 90 locations that perform mammographies under OBSP. ICMS prints mammography result letters to be sent to the client and their family physician and automatically generates recall letters. ICMS generates QA reports, monthly statistics and Program result data for CCO Evaluation.
Database Contents:	The ICMS database includes client demographic data, mammography result data, physician data and visit data.
Usage:	The users of ICMS are primarily clerical staff at the 90 OBSP sites throughout the province. These include Booking clerks, Data entry clerks and Medical coordinators.

Cervical Screening Program

Description:	The purpose of the Cervical Screening Program is to increase recruitment of women for regular Pap tests, facilitate appropriate follow-up, monitor the services provided, and evaluate outcomes. The primary goal of the Program is to reduce mortality from Cervical cancer by 100 each year. The information system currently used by the Cervical Screening Program is called Cytobase. Cytobase is a commercial database containing results on all Pap tests performed by private labs (approximately 80% of Pap tests performed in Ontario).
Functionality:	The data is used by CCO for aggregate data analyses of Pap test uptake within the constraints of the incompleteness of the data. INSCYTE, the not for profit corporation which owns Cytobase, also uses the data to support laboratory operations ie. Participating labs can access data relevant to their own patients.
Database Contents:	The database contains only Pap test results for 80% of all Pap tests performed in Ontario. It does not contain information on who should come in for screening or outcomes of definitive tests.
Usage:	Staff in the screening unit of the Division of Preventive Oncology are the users of the data at CCO. The data has not been linked to any other data files held by CCO e.g. Ontario Cancer Registry

e-Epicor

Description:	The purpose of e-Epicor system is to manage CCO's financial accounting and reporting requirements. e-Epicor is installed at P.O. and in each of the Regional Cancer Centres.
Functionality:	The functionality includes processing purchase orders, vendor vouchers, creating financial reports and processing payments.
Database Contents:	The database contains the history for general ledger accounts as well as vendor information.
Usage:	The system is used by all finance department staff at the Regional Cancer Centres and Provincial Office. The reporting module is used by all department heads, managers and vice-presidents.

Human Resource Information System (HRware)

Description:	HRware is a distributed human resource information system which centrally processes CCO employee career and compensation data for employees with multiple positions, salaries and department allocations. An interface to Ceridian, the CCO payroll system, provides single point of data entry, with most of the payroll data originating from HRware.
Functionality:	HRware consists of a variety of functional modules including employee personnel administration relating to benefits, leave, vacation, position/headcount, pension, termination and severance, disability absence, training and development, work force planning, occupational health and safety, employment equity, job requisitioning, applicant tracking, succession planning, compensation and job evaluation.
Database Contents:	The database contains employee personal data, compensation (hours worked + salary or hourly rate), benefit calculations and deduction amounts, employee career data, union data,, salary ranges by compensation group, educational institutions and job classification grades. The database includes employee-specific regional and general ledger identifiers.
Usage:	HR managers and administrators, finance managers and payroll administrators across CCO use HRware as an electronic database of current and historical employee data. Information is used for labour forecasting, succession planning and labour trends.

Ceridian Payroll System

Description:	Ceridian is a distributed payroll system which centrally processes CCO employee payroll data. Data entry, access and analysis is decentralized in the Regional Cancer Centres. Bi-weekly compensation data is transmitted to Ceridian for processing and paycheque generation.
Functionality:	Ceridian provides functionality for payroll administration.
Database Contents:	The Ceridian database contains employee personal data, compensation (hours worked + salary or hourly rate), benefit calculation and deduction amounts, statutory deductions/exemptions (EI rate, tax rate), other deduction amounts (union dues, parking, staff fund), absence time (sick and vacation), vacation, sick and lieu time banks and general ledger account data for the finance system.
Usage:	Direct users of Ceridian include payroll administrators and human resource administrators. Finance administrators use information from Ceridian for GL imports to the finance system and for Salary and Wage Analysis reports. The information is used to determine actual compensation cost for CCO by RCC and by department. Approximately 80% of the GL codes for Finance are derived from Payroll.

Content Management

Description:	The Content Management system is an integrated electronic sharing and data management tool using Hummingbird software. Hummingbird was selected as the software vendor based on a competitive tendering process. The system has 3 components linked together through a portal application. The three components are a document management application (Cyberdocs), a collaboration tool (PDAccord), and a search engine (fulcrum).
Functionality:	This system allows electronic sharing and collaboration of documents across CCO. Functionality also includes posting of documents to the corporate Intranet and the corporate website.
Database Contents:	The system will contain any document that may have use to others in the organization (e.g., webpages, user manuals, policies, procedures, project files)
Usage:	All CCO employees

Smart Systems for Health (SSH)

Description:	Cancer Care Ontario uses Smart Systems for Health (SSH) to create the CCO wide area network that allows communication between the Regional Cancer Centres and Provincial Office. CCO has built a VPN tunnel using the SSH Internet service to provide secure and rapid communication between the eight Regional Cancer Centres, Grand River Interim Regional Cancer Centre, the Program in Evidence Based Care and Provincial Office. CCO has implemented firewall technology between the SSH network and each of its sites to provide additional security to CCO information resources.
Functionality:	The SSH connection provides secure and rapid communication between CCO sites and network access to centralized systems and information resources.
Database Contents:	Not applicable
Usage:	The SSH connection is used by the eight regional cancer centres to access the centralized Payroll system and the centralized Human Resource Information Management system, and to submit Activity Level Reporting (ALR) data to Provincial office. It is used by Provincial Office to provide remote systems support to the RCCs for OPIS, OPIS 2000, IMPAC and other systems. The SSH connection is used by some RCCs for access to the Internet. Finally it is used for e-mail communication between all CCO sites.

Appendix 3b: Comparative Summary of IM Resources at Regional Cancer Centres

	Information Management Resource	GRRCC	HRCC	KRCC	LRCC	NEORCC	NWORCC	ORCC	T-SRCC	WRCC	Provincial Office
Clinical Systems	Oncology Information System	McKesson	OPIS	OPIS	OPIS	OPIS	OPIS	OPIS	OPIS	OPIS; Lotus Notes eChart	OPIS/OPIS 2000
	Radiation Systems		ADAC/ Pinnacle	VARIS; Theraplan	VARIS; Theraplan Plus; Acquism	Lantis/Helax	Lantis; Theraplan	Lantis; Plato; Theraplan; Xknife	Theraplan; Lantis; Plato; MMS; Corvis; Film Dosimetry	IMPAC; Plato; VARIS; Theraplan	
	Registration/ADT/CPI	STAR	OPIS	PCS	OPIS	OPIS	OPIS	OPIS	PCS	OPIS	
	Patient Scheduling System	HBOC PHS	OPIS	OPIS	OPIS	OPIS	OPIS	OPIS	OPIS	OPIS	
	Chemotherapy Order Entry	Horizon Orders	OPIS 2000	OPIS 2000	OPIS 2000	OPIS 2000	OPIS 2000	OPIS 2000	OPIS 2000	OPIS 2000	
	Dictation and Transcription	Lanier	Dictaphone; OPIS	Dictaphone; OPIS	Lanier; OPIS	Dictaphone; OPIS	Dictaphone; OPIS	Dictaphone; OPIS	Dictaphone	Lanier; Lotus Notes	
	Pharmacy System	STAR Pharmacy	Kroll		Kroll	Clinical Pharmacist	Clinical Pharmacist	Cerner	Kroll		
	Patient / Physician	STAR	ABEL	ABEL	ABEL	P&P CIS	Outsourced	MDS 5000	ABEL	ABEL	
	Ontario Breast Screening Program										ICMS/ Daedalian
	Genetics Program										FBCR/FCCR/Bios/GTAS
	Cervical Screening Program										Cytobase
	Prevention										Nvivo; Nudis
Management Systems	Registry System										OCRIS
	PIMS										PIMS
	PEBC										PEBC Web-site
	NDFP										MST
	Clinical Trials (SAS)						Homegrown		SAS		
	Library		Eloquent; Subscriptions/Journals	Outsourced to Queen's				DBText	Integrated Library; Ovid; Virtual Library		Virtual Library
	Other -										CRO DB Referral
Business Systems	Financials (GL, AP, PL, IC)	Medisolution	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore	Platinum/ Epicore
	Payroll/HR	Medisolution	Ceridian	Ceridian	Ceridian	Ceridian	Ceridian	Ceridian	Ceridian	Ceridian	Insync/HR Ware
	Fundraising System		Raisers Edge	Raisers Edge	Raisers Edge	Raisers Edge	Raisers Edge				
	Decision Support (DS Web/ALR)	TREND STAR; DS Web	DSWeb/ Impromptu	DSWeb/ Impromptu	DSWeb; Impromptu	DSWeb; Impromptu; Inhouse web reports	DSWeb/ Impromptu	DSWeb/ Impromptu	DSWeb/ Impromptu	DSWeb/ Impromptu	DSWeb/ Impromptu

Appendix 3c: High Level Summary of Major Applications at Host Hospitals

	Host Hospital Application	Grand River Hospital	Hamilton Health Sciences Centre	Kingston General Hospital	London Health Sciences Centre	Sudbury Regional Hospital	Thunder Bay Regional Hospital	Ottawa Hospital	Sunnybrook & Womens College	Windsor Regional Hospital
Clinical	**Main Application**	**Mckesson STAR**	**Meditech**	**Per Se Patient 1**	**Cerner**	**Meditech Client Server**	**Meditech**	**OaCIS**	**OaCIS**	**Mckesson STAR**
	ADT	STAR	Meditech	Per Se Patient 1	Cerner HNA Millenium	Meditech	Meditech	SMS	PCS	STAR Patient Processing
	Order Entry	Horizon Orders	Meditech				Meditech	Cerner	OaCIS	Care Manager
	Dictation & Transcription	Lanier	Dictaphone	Dictaphone/ Patient 1	Dictaphone	Voice Power 2000/ Meditech ITS	Lanier/ Meditech	Dictaphone	Dictaphone	Lanier
	Pharmacy	STAR Pharmacy	Meditech	BDM	Cerner	Meditech	Meditech	Cerner	Kroll	STAR Pharmacy
	Patient Scheduling	PHS	Meditech	Per Se Patient 1	Cerner HNA Millenium	Meditech	Meditech	SMS	PAS + others	
	Imaging/Radiology	STAR Radiology	Meditech ITS	Per Se Patient 1		Meditech ITS	Meditech	ALI	PACS Web1000 and IDX	STAR Radiology
Laboratory	**Biochemistry**	ALG	Meditech	Eclipsys LabVision	Cerner HNA Millenium	Meditech	Meditech		Sunquest	Triple G
	Hematology	ALG	Meditech	Eclipsys LabVision	Cerner HNA Millenium	Meditech	Meditech		Sunquest	Triple G
	Microbiology	ALG	Meditech	Eclipsys LabVision	Cerner HNA Millenium	Meditech	Meditech		Sunquest	Triple G
	Pathology	CoPath	Meditech	Eclipsys LabVision	Cerner HNA Millenium	Meditech	Meditech		CoPath	Triple G
	Bloodbank		Meditech	Eclipsys LabVision	Cerner HNA Millenium	Meditech	Meditech		Sunquest	Triple G
Other	**Decision Support**	TrendSTAR		Per Se Decision 1		Cognos				TrendSTAR
	Coding and Abstracting	Med 2020		Med 2020		Meditech, MED2020 (WinREX)	Cactus Abstract32 and Cactus CCare		Meditech	3M
	Financial Application	Medisolution	PeopleSoft	SAP		Meditech	IHS, Heron, Computerease			Infinium
	Interface Application	Cloverleaf	Datagate	e*Gate		None	CAI		CAI	Cloverleaf

Appendix 3d: Key Financial Analysis Based on 2001/02 IM Expenditure Data

Data related to information management were collected from the eight RCCs and provincial office for fiscal year 2001-2002 for the purpose of analyzing the organizational IM spending by RCC and common spending categories. For the purpose of this exercise, a broad definition of IM was used. This was done to capture all relevant costs associated with the IM spending within CCO and to have the ability to separate out the specific cost categories during the analysis if needed. The definition of IM includes all IT costs, all Health Record Costs and all cost associated with system support, system training and system maintenance outside of the IT and Health Records departments.

The purpose of this financial analysis was to provide a high level overview of the IM spending within CCO and to provide context and scale to further understand the starting point of the strategy. The data were not collected with the intent of inter-regional comparisons, and readers are cautioned from using them for this purpose.

Overview of CCO IM Spending

- CCO spent $25.2M in fiscal 2001-2002 on IM including Health Records. This represents 8.24% of the total CCO annual budget. Spending on Health Records totaled $6.8 million last year. Without Health Records, IM spending accounted for 6.0% of the total CCO budget.36% of IM spending occurs at Provincial Office and is related to Provincial programs (e.g. screening), Surveillance and Analysis (e.g. the Ontario Cancer Registry) and administrative systems.
- A suitable provincial agency could not be found to benchmark against CCO's information management spending. Other provincial health care organizations considered do not have the broader mandate of CCO that includes specialized applications such as the Ontario Cancer Registry.
- During the data collection process, Health Records spending data was received. However for analysis, the Health Records data was treated separately. The graphs below do not include Health Records spending.

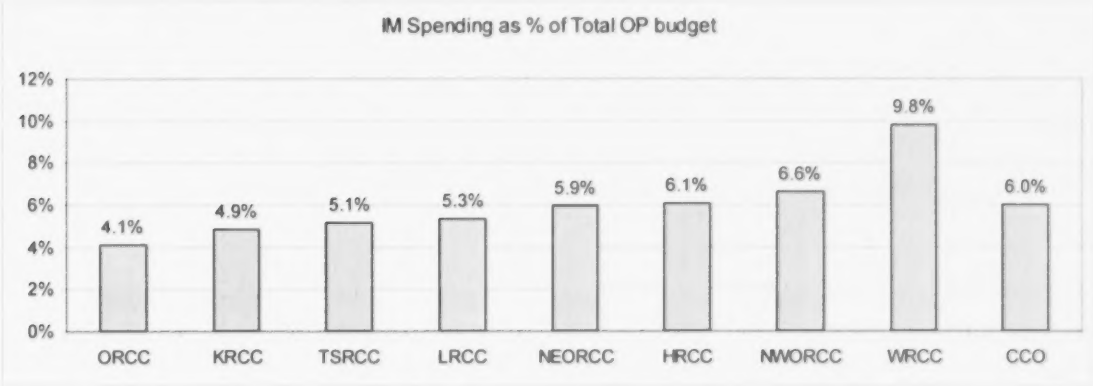
CCO Information Management Spending Categories:

CCO IM Annual Spending (Millions)	
Category	**Total**
Health Records	$6.8
Provincial Programs	$3.5
Surveillance and Analysis	$2.5
Desktop	$2.4
Network	$2.2
Clinical Systems	$1.4
Management and Administration	$1.4
Business and Finance Systems	$1.2
Radiotherapy Planning Systems	$1.2
Other	$0.7
Communications	$0.9
Helpdesk	$0.5
Clinical Trials	$0.4
Total	**$25.1**

Cost per visit*:

**Visit data is taken from ALR 2001/02, Total Visits (T1)*

Percentage of Total Operating Budget:



Summary of IM and Health Records Spending

	IM Spending (,000s)	Health Record Spending (,000s)	Total (,000s)	Total Treatment Visits
Provincial Office	$8,999	$0	**$8,999**	0
Hamilton RCC	$1,761	$1,135	**$2,896**	213,817
Kingston RCC	$662	$588	**$1,250**	80,529
London RCC	$1,396	$1,204	**$2,600**	156,701
Northeast Ontario RCC	$974	$527	**$1,501**	86,126
Northwest Ontario RCC	$618	$344	**$962**	45,928
Ottawa RCC	$1,249	$1,418	**$2,667**	166,179
Toronto Sunnybrook RCC	$1,583	$1,270	**$2,854**	208,912
Windsor RCC	$1,001	$365	**$1,366**	45,993
Total	**$18,298**	**$6,851**	**$25,095**	**1,004,185**

Appendix 4: Retreat Summary

Background

On September 25, 2002, Cancer Care Ontario (CCO) hosted a retreat, *Partners in Cancer Care: Building a Quality Improvement Coalition.* The retreat was an important step in an ongoing process to develop a comprehensive and integrated cancer program for Ontario. This concept was advanced by the Cancer Services Implementation Committee[4] which recognized that such a program will only be achieved with the participation of all key players in cancer care. Although the Committee acknowledged that CCO needed to strengthen its role as principal advisor to the Minister of Health and Long-Term Care on all matters related to the cancer control system and cancer control services, the Committee underscored the need for this advice to be informed by CCO's stakeholders. The retreat provided an ideal opportunity for a broad range of partners in cancer care to participate in the process of developing a provincial cancer strategy.

The Cancer System Information Management Strategy Steering Committee, chaired by Margaret Mottershead and including broad representation from the cancer care system, guided the planning, background work and widespread consultations that were conducted in preparation for the retreat. (See Appendix 2 for the members of the committee.) This work included the following:

- An extensive environmental scan informed the design of the retreat. The scan included data collection and interviews that were conducted with over 120 people from June to September, 2002. Representatives of regional cancer centres, host hospitals, and selected community hospitals that provide cancer care were interviewed, as well as representatives of the Ministry of Health and Long-Term Care, Cancer Care Ontario, the Ontario Cancer Research Network, professional groups, agencies responsible for other parts of the health system and a variety of other organizations. Interviewees included chief executive officers, chief information officers, and clinical and administrative staff providing or supporting patient care. Those interviewed were asked for their opinions on cancer system priorities and information management initiatives.
- Briefings were developed on eight cancer system priorities and 13 cancer information management initiatives to support the system priorities. These priorities and initiatives were identified through the consultations. In preparation for the retreat, these briefings were pre-circulated to participants for their review.

The retreat included a number of invited speakers as well as facilitated group discussions. (See Attachment 4.1 for the retreat agenda.) The invited speakers were:

- The Honourable Tony Clement, Minister of Health and Long-Term Care who announced the Cancer Quality Council;
- Tom Closson, Chair of the OHA Hospital eHealth Council, and President and Chief Executive Officer of the University Health Network;
- Dr. Warren McFarlan, Albert H. Gordon Professor of Business Administration at the Harvard Business School;
- Linda Lizotte-MacPherson, President and CEO of Canada Health Infoway, Inc.; and
- Vickie Kaminski, President and Chief Executive Officer, Sudbury Regional Hospital.

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[4] *Report of the Cancer Services Implementation Committee* (Alan R. Hudson, Chair). Submitted to The Honourable Tony Clement, Minister of Health and Long-Term Care, December 2001.

The retreat was attended by approximately 190 people representing a broad range of stakeholders including CCO board members and employees, physicians, other clinicians who provide direct patient care, researchers, administrators, staff who directly support those who provide patient care and government representatives. (See Attachment 4.2 for the list of retreat invitees.)

Proceedings of the Retreat

General Comments

One of the key objectives of the retreat was to give participants the opportunity to voice opinions on the relative importance of the cancer system priorities and information management initiatives that were identified in the consultations. Retreat participants were put into groups that reflected a mix of individuals with different backgrounds and experiences. Everyone was asked to rank system priorities and IM initiatives from their individual perspective. Individual rankings were consolidated into group rankings, and both sets of rankings were discussed in the facilitated breakout sessions. These discussions focused on the relative merits of the priorities, and the criteria used by participants to select their priorities. Participants were also invited to identify additional priorities. At the end of the breakout sessions, individuals and groups were given the opportunity to change their rankings. The final group and individual rankings are presented in this report.

The facilitated discussions provided an opportunity for diverse groups of individuals to discuss their opinions and work towards trying to achieve consensus on cancer priorities and related IM initiatives. A number of observations were made on the group process.

- Since explicit criteria for ranking the priorities were not provided, retreat participants used their own criteria in the ranking process. These criteria were documented during the group discussions. Although this approach was viewed by some as impacting on the rigour of the ranking process, it had the advantage of encouraging participants to identify the criteria that were most important to them. Some of these criteria included whether a priority:
  - Had short- or long-term impact;
  - Provided the best return on investments made;
  - Had an early impact on improving patient care;
  - Was already being developed;
  - Represented a critical gap that needed to be filled; and
  - Was feasible and easily implemented.
- Although priorities were presented as discrete items, dependencies existed between some of the priorities which made the ranking task more challenging.
- Some participants identified supportive and palliative care as additional priorities that needed to be acknowledged.

While all cancer system priorities and information management initiatives are important, a relative ranking helped in making decisions about the sequencing and speed of implementation. The following two sections present the ranking of cancer system priorities and information management initiatives.

Ranking of Cancer System Priorities

There are a wide range of opportunities to improve the cancer system. Retreat participants were asked to review a list of eight priorities and rank the items from 1 (highest) to 8 (lowest). The eight priorities were:

- Improving access management for cancer care services;
- Integrating service delivery;
- Supporting evidence-based care and improving patient safety;
- Monitoring outcomes and targeting areas for quality improvement;
- Increasing early detection of cancer through screening;
- Preventing cancer through reduced exposure to known risks;
- Improving cancer system planning; and
- Enhancing infrastructure for cancer research.

Table 4.1 compares 15 group and 129 individual rankings of cancer system priorities. Median rankings are provided as well as two measures of range: 25-75th percentile and minimum-maximum rankings. A score of "1" is the highest priority and "8" is the lowest.

A number of observations are evident from Table 4.1:

- There is a great deal of consistency in the median scores for each priority regardless of whether the group or individual did the ranking.
- Four priorities seemed to "float to the top" for both groups and individuals. These were: *i) improving access management for cancer care services; ii) integrating service delivery; iii) supporting evidence-based care and improving patient safety;* and *iv) monitoring outcomes and targeting areas for quality improvement.* These four priorities received both group and individual median scores ranging from 1-3.
- The remaining four priorities were ranked as having less relative importance by both groups and individuals. *Enhancing infrastructure for cancer research, increasing early detection of cancer through screening, improving cancer system planning, and preventing cancer through reduced exposure to known risks* received group and individual median scores of 6 or 7.

Table 4.1: Cancer System Priorities by Group and Total Individual Rankings (Median Ranking and Range)*

Priorities	Median Ranking and Range (25-75th Percentile and Minimum-Maximum)	
	Group (N=15)	Individuals (N=129)
Improving Access Management for Cancer Care Services	**1** 25-75th percentile = 1-1 (min-max = 1-2)	**1** 25-75th percentile = 1-3 (min-max = 1-8)
Integrating Service Delivery	**3** 25/75th percentile = 2-3 (min-max = 2-4)	**3** 25-75th percentile = 2-5 (min-max = 1-8)
Supporting Evidence-Based Care and Improving Patient Safety	**3** 25/75th percentile = 2-4 (min-max = 1-4)	**3** 25-75th percentile = 3-4 (min-max = 1-8)
Monitoring Outcomes and Targeting Areas for Quality Improvement	**3** 25/75th percentile = 3-4 (min-max = 1-7)	**3** 25-75th percentile = 2-5 (min-max = 1-8)
Enhancing Infrastructure for Cancer Research	**6** 25/75th percentile = 5.5-7 (min-max = 4-8)	**6** 25-75th percentile = 5-7 (min-max = 1-8)
Increasing Early Detection of Cancer Through Screening	**6** 25/75th percentile = 5-7 (min-max = 3-8)	**6** 25-75th percentile = 5-7 (min-max = 1-8)
Improving Cancer System Planning	**6** 25/75th percentile = 5-8 (min-max = 5-8)	**6** 25-75th percentile = 5-8 (min-max = 1-8)
Preventing Cancer Through Reduced Exposure to Known Risks	**7** 25/75th percentile = 6-8 (min-max = 5-8)	**7** 25-75th percentile = 5-8 (min-max = 1-8)

* One is the highest priority and eight is the lowest.

Table 4.2 explores the rankings in more depth by assessing the median scores in relation to the dispersion of the scores as reflected by the interquartile range (25-75th percentile or the middle 50% of responses) and the minimum-maximum range. Such a comparison sheds light on any variation in the ranking of two priorities that have the same median score.

Table 4.2: Summary of Cancer System Priority Rankings by Group and Total Individual Rankings*

Top Four Priorities	Group (N=15)	Individual (N=129)
Improving Access Management for Cancer Care Services	1	1
Integrating Service Delivery	2	2 (tie)
Supporting Evidence-Based Care and Improving Patient Safety	3	3
Monitoring Outcomes and Targeting Areas for Quality Improvement	4	2 (tie)
Additional Four Priorities		
Increasing Early Detection of Cancer Through Screening	5	4 (tie)
Enhancing Infrastructure for Cancer Research	6	4 (tie)
Improving Cancer System Planning	7	5
Preventing Cancer Through Reduced Exposure to Known Risks	8	6

*One is the highest priority and eight is the lowest. The rankings have been developed by assessing the median scores, and the dispersion of scores as reflected by the interquartile range (25-75th percentile) and the minimum-maximum range.

A review of Table 4.2 indicates slight differences between group and individual rankings for the top four priorities. In the individual rankings, two priorities tied for second place – *integrating service delivery*, and *monitoring outcomes and targeting areas for quality improvement.* In addition, two priorities tied for fourth place.

Ranking of Information Management Initiatives

There are a wide range of potential information management initiatives that support the cancer system priorities. Retreat participants were asked to review a list of 13 priorities and rank the items from 1 (highest) to 13 (lowest). The 13 initiatives were:

- Referral management and wait list tracking system;
- Pathology information management system (PIMS);
- Capturing clinical stage information;
- Surgical activity tracking;
- Systemic therapy management system;
- Radiation therapy management system;
- Regional electronic health record initiatives;
- Clinical trials enrollment and management;
- Clinical databases to support tumour banking;
- Provincial human resource planning system;
- Screening tracking system;
- Guideline use tracking system; and
- Enhancement to the Ontario Cancer Registry.

Table 4.3 compares 15 group and 103 individual rankings of cancer IM priorities. Median rankings are provided as well as two measures of range: 25-75th percentile and minimum-maximum rankings. A score of "1" is the highest priority and "13" is the lowest.

A number of observations are evident from Table 4.3:

- There is a great deal of consistency in the group and individual rankings when median scores are examined. Some variation occurs in initiatives that have median scores that reflect a lower priority. For example, the groups gave *clinical trials enrollment and management* a median score of 11 whereas the individuals gave this initiative a score of 9.
- Both groups and individuals agreed on the top seven initiatives when median scores are examined. The first initiative for groups and individuals was *referral management and wait list tracking system.* This was closely followed by the *pathology information management system* which received a median score of 2 from the groups. Although individuals also ranked this initiative as the second priority, they gave it a lower median score of 3.

Table 4.3: Cancer IM Initiative Priorities by Group and Total Individual Rankings (Median Ranking and Range)*

Initiatives	Median Ranking and Range (25-75th Percentile and Minimum-Maximum)	
	Group (N=15)	Individuals (N=103)
Referral Management and Wait List Tracking System	**1** 25-75th percentile = 1-1 (min-max = 1-2)	**1** 25-75th percentile = 1-2 (min-max = 1-8)
Pathology Information Management System (PIMS)	**2** 25/75th percentile = 2-3 (min-max = 1-5)	**3** 25-75th percentile = 2-5 (min-max = 1-11)
Surgical Activity Tracking	**3** 25/75th percentile = 3-4 (min-max = 2-7)	**4** 25-75th percentile = 3-6 (min-max = 1-12)
Capturing Clinical Stage Information	**4** 25/75th percentile = 3-5 (min-max = 2-6)	**4** 25-75th percentile = 3-6 (min-max = 1-12)
Regional Electronic Health Record Initiatives	**5** 25/75th percentile = 4-6 (min-max = 2-13)	**5** 25-75th percentile = 3-9 (min-max = 1-13)
Systemic Therapy Management System	**6** 25/75th percentile = 5-6 (min-max = 3-6)	**6** 25-75th percentile = 5-7 (min-max = 1-12)
Radiation Therapy Management System	**7** 25/75th percentile = 7-9 (min-max = 2-10)	**7** 25-75th percentile = 6-10 (min-max = 2-13)
Guideline Use Tracking System	**9** 25-75th percentile = 8-9 (min-max = 7-12)	**9** 25-75th percentile = 7-11 (min-max = 1-13)
Provincial Human Resources Planning System	**10** 25-75th percentile = 8-12 (min-max = 4-13)	**11** 25-75th percentile = 7-13 (min-max = 1-13)
Clinical Trials Enrollment and Management	**11** 25/75th percentile = 9-11 (min-max = 5-13)	**9** 25-75th percentile = 8-11 (min-max = 2-13)
Screening Tracking System	**11** 25-75th percentile = 9-12 (min-max = 8-13)	**10** 25-75th percentile = 9-12 (min-max = 1-12)
Enhancement to the Ontario Cancer Registry	**11** 25-75th percentile = 10-12 (min-max = 8-13)	**10** 25-75th percentile = 8-12 (min-max = 1-13)
Clinical Databases to Support Tumour Banking	**12** 25-75th percentile = 10-13 (min-max = 7-13)	**10** 25-75th percentile = 9-12 (min-max = 3-13)

*One is the highest priority and 13 is the lowest.

Table 4.4 explores ranking in more depth by assessing the median scores in relation to the dispersion of scores as reflected by the interquartile range (25-75th percentile or the middle 50% of responses) and the minimum-maximum range.

Table 4.4: Summary of Cancer IM Initiative Rankings by Group and Total Individual Rankings*

Priorities	Group (N=15)	Individual (N=103)
Referral Management and Wait List Tracking System	1	1
Pathology Information Management System (PIMS)	2	2
Surgical Activity Tracking	3	3 (tie)
Capturing Clinical Stage Information	4	3 (tie)
Regional Electronic Health Record Initiatives	5	4
Systemic Therapy Management System	6	5
Radiation Therapy Management System	7	6
Guideline Use Tracking System	8	7
Provincial Human Resources Planning System	9	11
Clinical Trials Enrollment and Management	10	8
Screening Tracking System	11	10 (tie)
Enhancement to the Ontario Cancer Registry	12	9
Clinical Databases to Support Tumour Banking	13	10 (tie)

*One is the highest priority and 13 is the lowest. The rankings have been developed by assessing the median score, and the dispersion of scores as reflected by the interquartile range (25-75th percentile) and the minimum-maximum range.

A review of Table 4.4 indicates slight differences between group and individual rankings for the top seven priorities. In the individual rankings, two priorities are tied for third place – *surgical activity tracking* and *capturing clinical stage information.* There is more variation between group and individual rankings for initiatives that have median scores of 8 and higher.

Retreat Evaluations

Evaluations were completed by 67 of participants who generally, evaluated the retreat highly. (See Attachment 4.3 for the evaluation results.)

Next Steps

The proceedings from the retreat are part of a process to develop a cancer services strategy document. The strategy will incorporate input from the interviews conducted in preparation for the retreat as well as the input obtained from retreat participants and will consider additional factors such as:

- The need to keep all stakeholders engaged and manage the rate of change so that it does not become overwhelming;
- The desire to build on existing structures, programs and initiatives, capitalizing on the progress that has been made to improve the quality of cancer care;
- The availability of appropriate technology (especially software and standards);
- The need to integrate plans with the initiatives of Smart Systems for Health, Canada Health Infoway and individual provider organizations; and
- The availability of financial resources for implementation.

Attachment 4.1: Retreat Agenda

PARTNERS IN CANCER CARE:
BUILDING A QUALITY IMPROVEMENT COALITION
Hosted by Cancer Care Ontario

Wednesday, September 25, 2002, 9:00 a.m. – 4:30 p.m.
at
Metropolitan Hotel Toronto
108 Chestnut Street
Toronto Ballroom, 2nd Floor

Registration	**8: 30-9:00 a.m.**
Welcome and Overview of the Day Dr. Alan Hudson, President and CEO, Cancer Care Ontario Tom Closson, Chair of the OHA Hospital eHealth Council, and President and CEO of UHN-PMH	**9:00-9:30 a.m.**
Address From the Minister of Health and Long-Term Care Honourable Tony Clement	**9:30-9:50 p.m.**
Succeeding in the IT Intensive World of the 21st Century Dr. Warren McFarlan, Harvard Business School	**9:50-10:50 a.m.**
Ranking Cancer System Priorities Ian Brunskill, CIO and Vice President Planning, CCO Dr. Michael Guerriere, Partner, Courtyard Group	**10:50-11:10a.m.**
Breakout Groups	**11:10-12:40 p.m.**
Lunch	**12:40 – 1:30 p.m.**
Update on Canada Health Infoway Linda Lizotte-MacPherson, President and CEO Canada Health Infoway Inc.	**1:30 – 2:00 p.m.**
Ranking Information Management Initiatives Ian Brunskill and Dr. Michael Guerriere	**2:00 – 2:30 p.m.**
Breakout Groups	**2:30 – 3:45 p.m.**
The Coalition Concept Vickie Kaminski, President and CEO, Sudbury Regional Hospital	**3:45 – 4:00 p.m.**
Reporting Back Ian Brunskill and Dr. Michael Guerriere	**4:00 – 4:20 p.m.**
Closing Remarks and Next Steps Peter Crossgrove, Chair of the Board, Cancer Care Ontario Dr. Alan Hudson, President and CEO, Cancer Care Ontario	**4:20 – 4:30 p.m.**

Attachment 4.2: Retreat Invitees

Name		Primary Group	Location/Position
Aberman	Arnie	Other - hospital	U of T Faculty of Medicine
Abu-Zahra	Hakam	Executive Management	WRCC
Anderson	Matt	Other - hospital	UHN
Angus	Helen	PAMNet	Provincial CCO Office
Ashcroft	James W.	CCO Board	
Baker	Michael	Other - hospital	UHN
Beattie	Diane	Host Hospitals	London Health Sciences Centre
Bell	Robert	Steering Committee	University Health Network
Berman	Neil	Other	Cdn Strat for Ca Control
Bissett	Randy	Steering Committee	NEORCC
Boecker	Stewart	Steering Committee	University Health Network
Boger	Netanis	MOHLTC	MOHLTC, Toronto
Bondy	Susan	Other	ICES
Bouchard	Maurice	IMCC	KRCC
Bowie	Jamie	Host Hospitals	Credit Valley Hosp.
Boyd	Jane	CCO Board	
Bradshaw	Jinnie	CCO Board	
Brouwers	Melissa	PCC	McMaster University
Browman	George	Executive Management	HRCC
Brown	Brian	Other	Ove Design & Communications ltd.
Brown	David A.	CCO Board	
Brunskill	Ian	Executive Management	Provincial CCO Office
Cairncross	Gregory	Executive Management	
Callum	John	Host Hospitals	Lakeridge Health Corp
Carter	Brenda	PAMNet	LRCC
Chambers	Brent	CCO Board	
Claiter	Catherine	Host Hospitals	Kingston General Hosp.
Clement	Tony	MoH	Minister
Closson	Tom R.	CCO Board	
Coghlan	Anne	Other	College of Nurses of Ontario
Connell	George	Other	Cancer Initiative Working Group
Connolly	Mike	MOHLTC	Smart Systems for Health
Cooper	Helen	CCO Board	
Cowan	Don	PCC	Provincial CCO Office
Crossgrove	Peter	CCO Board	
Cushman	Robert	Other	Ottawa Carlton HU
Dagnone	Tony	CCO Board	London Health Sciences Centre
Dale	Darlene	Other - hospital	UHN
de Mora	Joseph	CCO Board	

Name		Primary Group	Location/Position
Decter	Michael	Quality Council	CIHI
Deeley	Roger	Executive Management	Queen's University, Research
Depetrillo	Denny	PCC	Provincial CCO Office
Dhaliwal	Harbhajan	Executive Management	NWORCC
Dickie	Cam	Host Hospitals	Windsor Regional Hospital
Dingle	Brian	Executive Management	GRRCC
Dixon	Peter	Executive Management	DRCC
Downey	Sarah	Other - hospital	UHN
Egan	Dennis	Host Hospitals	Grand River Hosp.
El-Jardali	Fadi	MOHLTC	(East Region)
Evans	William	Executive Management	Provincial CCO Office
Farrow	Mark	Host Hospitals	Hamilton Health Sciences Corp.
Favell	Lisa	PAMNet	Capital Projects Office
Fell	Fraser	CCO Board	
Fernandes	Perpetua	Other - CCO	Provincial CCO Office
Fine	Sheldon	Executive Management	PRCC
Fitch	Margaret	PCC	T-SRCC
Fitzsimmons	Deborah	PCC	Provincial CCO Office
Flett	Suzanne	Host Hospitals	Thunder Bay Regional Hospital
Francis	Myrna	Other	Canada Health Infoway
Freedman	Ted	Other	Change Foundation
Freeman	Laura	PAMNet	NEORCC
Fyffe	Wayne	Host Hospitals	Credit Valley Hosp.
Gagnon	Ron	Host Hospitals	Sault Area Hospital
Garcia	John	PCC	Provincial CCO Office
Germain	Dan	Host Hospitals	CVH
Germond	Colin	Other - CCO	NEORCC
Girash	Martin	Host Hospitals	Windsor Regional Hospital
Godel	Raylene	CCO Board	
Goh	Mary	IMCC	Provincial CCO Office
Golden	Brian	Other	U of T School of Business
Gordon	Dan	Other	Praxia Intelligence
Green	Esther	PCC	Provincial CCO Office
Guerriere	Michael	Steering Committee	Courtyard Group
Hassen	Phillip	MOHLTC	Deputy Minister
Hawley-Knowles	Gail	PAMNet	Lakeridge Health Corporation
Heydon	Angie	Executive Management	Provincial CCO Office
Hindo	Paul	CCO Board	
Hodgert	Brenda	PAMNet	Capital Projects Office
Holder	Glenn	MOHLTC	e-Physician project
Hollenberg	Charles	Other - CCO	Provincial CCO Office
Holowaty	Eric	Other - CCO	Provincial CCO Office

Name		Primary Group	Location/Position
Hudson	Alan	Executive Management	Provincial CCO Office
Hunet	Ozgur	Other - hospital	UHN
Hyatt	Sue	Other	Canada Health Infoway
Irvine	Andrew	MOHLTC	Health Care Programs, North Region
Jacobson	Lee	Other	Ove Design & Communications ltd.
Jadad	Alex	Other - hospital	UHN - TGH
Jadavji	Moyez	PAMNet	WRCC
Jamieson	Heather	PAMNet	Provincial CCO Office
Jenkins	Toby	CCO Board	
Jorgensen	Birthe	MOHLTC	MOHLTC, Toronto
Kaminski	Vickie	Host Hospitals	Sudbury Regional Hosp.
Kearns	Glen	Host Hospitals	Grand River Hosp.
Keating	Armand	Other - hospital	UHN - PMH
Khosla	Naresh	Executive Management	Provincial CCO Office
Kime	John	CCO Board	
Kitts	J.B. (Jack)	Host Hospitals	The Ottawa Hosp.
Klejman	Michael	MOHLTC	(Central East Region)
Kline	Donna	Executive Management	Provincial CCO Office
Kozlowich	Shane	Other - Courtyard Group	Courtyard Group
Kyle	Robert	Other	Public Health, Durham
Laakkonen	Allan W.	CCO Board	
Ladak	Nizar	Other	CIHI
Laforet	Renee	MOHLTC	MOHLTC, Toronto
Lamb	Alastair	PAMNet	KRCC
Langer	Bernard	Quality Council	Toronto General Hospital
Leatt	Peggy	Quality Council	University of North Carolina
Lecce	Sarina	Other - CCO	Consultant
Leib	Ryan	Other - CCO	Provincial CCO Office
Lemon	Brian	Host Hospitals	Lakeridge Health Corp
Lenz	Donald	CCO Board	
Levin	Les	MOHLTC	MOHLTC, Toronto
Linton	Rhonda	Other - Courtyard Group	Courtyard Group
Lizotte-MacPherson	Linda	Other	Canada Health Infoway
Macdonald	Marian	MOHLTC	e-Physician project
Mackenzie	Michael A.	CCO Board	
Mackillop	William	Quality Council	KRCC
Mackinnon	David	Other	OHA
MacNaughton	John	CCO Board	
Mai	Verna	PCC	Provincial CCO Office
Malkani	Manu	Host Hospitals	Sault Area Hospital
Marafioti	Sam	Host Hospitals	SWCHSC

Name		Primary Group	Location/Position
Markel	Frank	Other	JPPC
Marshall	Lori	Host Hospitals	Thunder Bay Regional Hospital
Martin	Murray	Host Hospitals	Hamilton Health Sciences Corp.
Martin	Perry	CCO Board	
Matheson	Garth	PAMNet	T-SRCC
McFarlan	Warren	Other	Harvard Business School
McGhee	Peter	Other - CCO	NWORCC, Physics
McGowan	Tom	Other	CROS
McGuire	Katharine G.	CCO Board	
McLeod	David	Other	OHA
Mercer	David	MOHLTC	MOHLTC, Toronto
Mercuri	Pat	PAMNet	Credit Valley Hospital
Mithani	Shamir	Other - CCO	Provincial CCO Office
Morgan	Matthew	Other	Per-Se
Mottershead	Margaret	Steering Committee	
Murray	Gail	Other	Change Foundation
Murray	Scott	Other	CIHI
Noble	Michele	Other	Cancer Initiative Working Group
Nolan	Catherine	Executive Management	Provincial CCO Office
Nori	Gerald	CCO Board	
Northan	Janet	IMCC	NWORCC
Nuttall	Sandy	MOHLTC	(Hospitals Branch)
Orovan	Janice D.	CCO Board	
Parrack	Denise	IMCC	LRCC
Paszat	Larry	Other	ICES
Pattenden	David	Other	OMA
Perri	Vincy	Other - CCO	Provincial CCO Office
Petersen	Ben	Host Hospitals	Sudbury Regional Hosp.
Phillips	Bob	Other	OCRN
Picciano	Gino	Host Hospitals	The Ottawa Hosp.
Pileggi	Vince	PAMNet	DRCC
Poldre	Peeter	PCC	Provincial CCO Office
Power	Michael	PAMNet	NWORCC
Rajaballey	Jenny	MOHLTC	(South West Region)
Rand	Carol	PAMNet	HRCC
Reid	Trudy	PAMNet	ORCC
Rennie	Michael	Host Hospitals	Niagara Health System
Reznick	Richard	Other - hospital	UHN - TGH
Roberts	Wayne	IMCC	Provincial CCO Office
Robertson	Sue	PAMNet	GRRCC
Roch	Jodie	Other - CCO	Provincial CCO Office
Ronson	John	Other - Courtyard Group	Courtyard Group

Name		Primary Group	Location/Position
Rose	Kurt	Other	OHA
Rosen	Barry P.	CCO Board	
Roy	Gaston	Host Hospitals	Sudbury Regional Hosp.
Sandiford	Charles	CCO Board	
Sawka	Carol	Executive Management	T-SRCC
Schwartz	Lisa	PCC	Provincial CCO Office
Scott	Graham	Other	McMillan Binch
Shah	Narendra	MOHLTC	(Central South Region)
Shapiro	Jack	Other	Consultant
Shedden	Sylvia	PAMNet	Provincial CCO Office
Sider	Doug	Other	Brant County Health Unit
Skot	Janice	Executive Management	NEORCC
Smith	Anne	Executive Management	KRCC
Snider	Anne	PAMNet	HRCC
Stern	Hartley	Executive Management	ORCC
Steven	Leo	Host Hospitals	SWCHSC
Stuart	Allison	MOHLTC	(Hospitals Branch)
Sullivan	Terry	Executive Management	Provincial CCO Office
Syed	Nash	Other - Courtyard Group	Courtyard Group
Taylor	Lorelle	MOHLTC	MOHLTC, Toronto
Taylor	Bryce	Other - hospital	UHN - TGH
Taylor	Don	PAMNet	Provincial CCO Office
Thomsen	Penny	Other	CCS Ont
Till	James	Other - hospital	OCI
Trypuc	Joann	Other	Facilitator
Viau	Michael	Other	Ove Design & Communications ltd.
Walker	Joanne	Other - Courtyard Group	Courtyard Group
Wattling	Dave	Other - Courtyard	Courtyard
Watts	Kathy	Host Hospitals	Hamilton Health Sciences Corp.
Watts	Linda	Host Hospitals	Sault Area Hospital
Weber	Marnie	MOHLTC	(Toronto Region)
Whittome	Helen	MOHLTC	MOHLTC, Toronto
Whitton	Anthony	PCC	Provincial CCO Office
Wilson	Jim	MOHLTC	Minister
Zanke	Brent	Other - CCO	CCO
Zelmer	Jennifer	Other	CIHI

Attachment 4.3: Retreat Evaluations

1. **The retreat will help guide the creation of a comprehensive integrated cancer program for Ontario.**

	Total	Percent
Strongly Agree	9	14%
Agree	31	48%
Somewhat Agree	21	32%
Disagree	3	5%
Strongly Disagree	1	1%
Total	65	100%

Average = 3.6/5. Missing = 2.

2. **The retreat met my expectations.**

	Total	Percent
Strongly Agree	13	21%
Agree	38	60%
Somewhat Agree	9	14%
Disagree	2	3%
Strongly Disagree	1	2%
Total	63	100%

Average = 3.7/5. Missing = 4.
Comments: No move to an integrated, comprehensive information model.

3. **Generally, the presentations at the retreat were informative and useful.**

	Total	Percent
Strongly Agree	23	35%
Agree	35	53%
Somewhat Agree	7	11%
Disagree	1	1%
Strongly Disagree	0	0%
Total	66	100%

Average = 4.2/5. Missing = 1.
Comments: Not challenging.
McFarlan and MacPherson extremely effective speakers.
Warren MacFarlane is awesome.

4. **The small group work was effective for obtaining widespread input into cancer system priorities and IM initiatives.**

	Total	Percent
Strongly Agree	15	23%
Agree	25	38%
Somewhat Agree	19	29%
Disagree	4	6%
Strongly Disagree	3	4%
Total	66	100%

Average = 3.6/5. Missing = 1.
Comments: Too parochial.

5. **Sufficient opportunity was available during the retreat to express my opinions.**

	Total	Percent
Strongly Agree	22	33%
Agree	40	60%
Somewhat Agree	4	6%
Disagree	0	0%
Strongly Disagree	1	1%
Total	67	100%

Average = 4.2/5.

6. **The range of groups represented at the retreat was good.**

	Total	Percent
Strongly Agree	17	26%
Agree	36	55%
Somewhat Agree	10	16%
Disagree	2	3%
Strongly Disagree	0	0%
Total	65	100%

Average = 3.9/5. Missing = 2.

Comments: Needed consumers.
Where are the patient, citizens, primary care providers, researchers?
Hard to tell without a participant list.

7. **The background material prepared for the retreat was helpful.**

	Total	Percent
Strongly Agree	18	27%
Agree	36	54%
Somewhat Agree	11	16%
Disagree	2	3%
Strongly Disagree	0	0%
Total	67	100%

Average = 4.0/5.

Comments: Needed palliative and supportive care priorities.
Confirmed that CCO's view was paternalistic and parochial.
Suggest include rating forms in package to focus preparation beforehand.

8. **The retreat was well organized (planning, communication).**

	Total	Percent
Strongly Agree	34	51%
Agree	31	46%
Somewhat Agree	2	3%
Disagree	0	0%
Strongly Disagree	0	0%
Total	67	100%

Average = 4.5/5.

Comments: Feedback system was good.
We could have arrived with our ranks.

9. **The format of the retreat was effective.**

	Total	Percent
Strongly Agree	21	32%
Agree	29	44%
Somewhat Agree	13	20%
Disagree	3	4%
Strongly Disagree	0	0%
Total	66	100%

Average = 4.0/5. Missing = 1.

10. **The location of the retreat was good.**

	Total	Percent
Strongly Agree	27	40%
Agree	34	51%
Somewhat Agree	2	3%
Disagree	3	5%
Strongly Disagree	1	1%
Total	67	100%

Average = 4.2/5.

Comments: Breakout rooms too far away. Elevator problem. Hotel for overnight at a different hotel than conference. Very inconvenient. Long distance from hotel accommodations.

11. **Did you feel that the retreat was:**

	Total	Percent
Right Length	55	86%
Too Short	6	9%
Too Long	3	5%
Total	64	100%

Missing = 3.

Comments: Very efficient and fast moving.

12. **Overall retreat grade**

Grade	Total	Percent
A	20	40%
A-	2	
B+	3	38%
B	18	
C+	1	15%
C	7	
D	4	7%
Total	55	100%

Missing = 12.

13. Check all that apply*

	Total
I am a physician	16
I provide direct patient care	14
I directly support those who provide patient care	16
I am a researcher	14
I am an administrator	45
I work for CCO	21
Other**	12

*Out of 67 respondents, 28 checked more than one category.

** Five participants noted that they were CCO Board Members.
One participant noted that he/she was a civil servant in Health .

14. Please provide any other comments you may have.

a. Patient perspective might have added to the discussion.

b. The huge problem with this retreat lay in the method of priority setting - far too superficial and facile. The results, therefore, are not substantive. Anyone could, therefore, now set substantive priorities arguing that the results of the retreat are supportive. There may be a backlash ultimately of people feeling used.

c. First rate day.

d. Should have reinforced system wide view for participants. Separate section focussed on user-get everyone thinking as a patient. What are patient's expectations for system-wide delivery would have been useful. There was a lot of "power" or change agents in the room. Need to have phase 2 to challenge/motivate players.

e. I understand the desire to seek widespread input and seek consensus, but don't be surprised when people continue to hold on to views of "it can't happen", "it won't happen." Just let the smart innovators run with it and we'll be wowed by results. Enough meeting; let's act!

f. Difficult to connect McFarlan's good speech to the issues facing CCO and the system. Likely a milestone event for CCO. Various incentives in the basic document ignored cost and revenue factors - don't financial limits play any role in determining priorities?

g. Unlike most workshops, where the objectives slowly become clear by the end of the day, this workshop began from a clear set of objectives and fulfilled or exceeded objectives.

h. Will require continued communication and follow-up but a very good start.

i. I was astonished and dismayed by the lack of representation from the primary care sector - that is family physicians. Otherwise, representation of various stakeholders was good.

j. Would have preferred to be given more structured method to prioritize as it was clear people ranked something high or low on very different bases (e.g., something already underway could rank high because of high feasibility, or low because it is already being done, therefore, there is less need to give it a high priority.

k. Important cross-cutting issues not addressed: 1) Problem gaining access to useful information including privacy; 2) The issues of assuring us about the quality of the information-accuracy, completeness, timeliness-could be a function of the new Quality Council; 3) patient/family/career information needs; 4) Primary care/surgery information needs; 5) Researcher information needs. IT initiatives should not be included before the strategic goals/priorities are articulated, program performance standards defined and performance indicators identified. Only then should IT strategies be designed to feed back useful information to decision makers.

l. Important to note that IT initiatives currently underway at CCO may be counterproductive to current vision and outcome of this retreat.

m. Found rating the cancer system priorities to be easier than the initiatives. Need more criteria to establish an objective method of rating. Need to establish a "oneness of purpose" then we can achieve Li and Fung type of results. Integration that makes sense should be a priority-why duplicate support resources (IT; HR).

n. Identification of present IM initiatives could have been clarified. Danger of future "silos" of data based on groupings of initiatives. Some participants did not have knowledge base to give informed input into the rankings or knowledge of potential impact on improving patient care and outcomes to determine ranking of initiatives.

o. Several of the cancer systems priorities are subsets. Ditto for the IM priorities. Hence, the rankings are distorted in unknown ways. So even narrow distributions may be seriously misleading as to consensus/readiness for change.

p. Well done!

q. Ranking exercise in small groups was not well planned and frustrating.

r. More contextual information should have been provided before breakout groups.

s. Please provide a list of participants with summary of retreat. What follow-up will be done with decision makers to ensure a strong collective voice to take forward to government?

t. A list of all attendees would have been helpful for the small group discussion. Even though there was an opportunity to introduce ourselves, it would have been a good reference. Community partners and patients may have provided a different perspective.

u. Leadership is needed to provide the connection between partners' "wish lists" and the $/resources available. Didn't the pre-consultations achieve the same result as this retreat?

v. The facilitator was great. Great use of humour by all speakers when in trouble with IT. Loved the speaker from Harvard.

w. Follow up is very important. Congratulations to organizers. Very relaxed - touched all levels in audience. Varied perspectives enhance abilities in decision making. This enthusiasm needs frequent revitalization. Palliative care/supportive care not mentioned.

x. Good background. Good mix of people. Not clear who would assume responsibility for the various initiatives listed. Would have been helpful to separate roles and responsibilities, and focus on what CCO can do and flag areas where coordination with others is needed. I found small group discussions interesting but did not see value of ranking. Each item contained too many components to give a specific ranking. In addition, many priorities were interdependent making ranking a difficult exercise.

y. Very well organized. Choice of guest speakers was excellent. Only improvement: warmer facility.

z. Will you provide copies of the presentations?

aa. As you move forward, I challenge you to be inclusive/comprehensive in your thinking about "cancer services". What will be included? There is an overwhelming sense in the documents and conversation that this is for physicians/surgeons and systemic/radiation/surgical care. There are other issues, other interventions and other players for whom this work applies. Could the writing at least reflect this even if the items are not on the priority list?

bb. Could have asked where do these initiatives fit in the Canadian context (i.e., not just Ontario).

Appendix 5: Information Infrastructure

OVERVIEW

The purpose of this appendix is to describe the information architecture necessary to support the development of a comprehensive, integrated cancer program.

The CCO Information Architecture is broken into three distinct layers or tiers. The first is the Clinical Application Tier, consisting of patient care systems that are used to collect and store patient data in a digital format and support the delivery of direct care. The second tier is the Integration Tier which ties the patient care systems together both within the hospital and across organizational boundaries to form the Electronic Health Record (EHR). This tier provides integration, linking, data extraction and transaction management services to support research, management and surveillance databases that reside in the Data Tier. The final tier is the Data Tier which consists of the logical and physical data stores used to support the initiatives identified in the Information Management Strategy. This three-tier architecture is depicted in Figure 5.1.

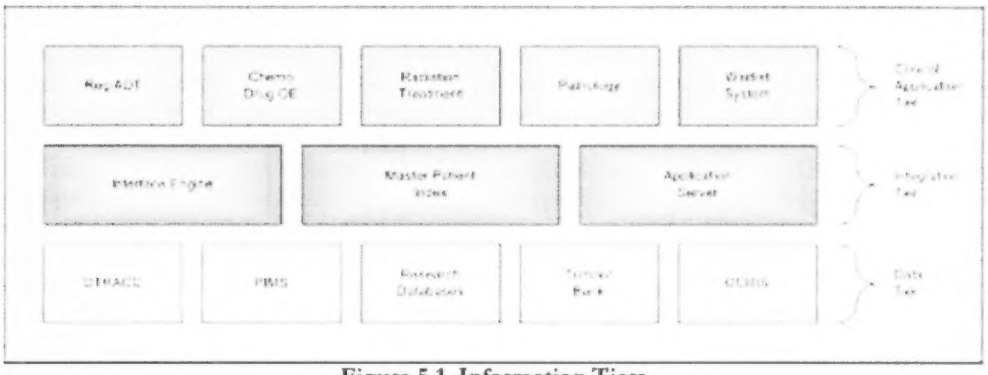

Figure 5.1. Information Tiers

CLINICAL APPLICATION TIER

The Clinical Application Tier consists of the clinical and relevant business applications that will reside within the hospital to directly support patient care. These are transactional systems that contain the source data that needs to be integrated to create both the Electronic Health Record (EHR) in the hospital or region and the management, surveillance and research databases required by CCO.

The CCO Information Management Strategy will establish Integrated Cancer Programs (ICP) resulting in closer organizational integration by leveraging common information systems thus reducing duplication. The ICPs will leverage existing hospital based-systems at the Clinical Application Tier where possible. CCO will establish standards to ensure adequate functionality in terms of process workflow and patient safety and that required data submissions for surveillance and funding purposes are available.

INTEGRATION TIER

Integration can be divided into the following:

- Intra-Hospital: the integration of disparate systems within the hospital; and
- Inter-Hospital: the integration of systems across hospitals and CCO.

Intra-Hospital Integration

To support the development of ICPs, investigation is needed to determine how cancer specific applications will be integrated or transferred into the hospital environment. While some integration may require vendor support, in many cases an Integration (Interface) Engine will be used to facilitate sharing and synchronizing data on the back end between the various patient care systems using system or protocol specific adapters. Logically, this can be thought of as a hub and spoke model, where external patient care systems share data through a centralized message broker that handles all issues relating to distributing these messages to all of the participating systems (see Figure 5.2). Integration Engines will be discussed further in the next section.

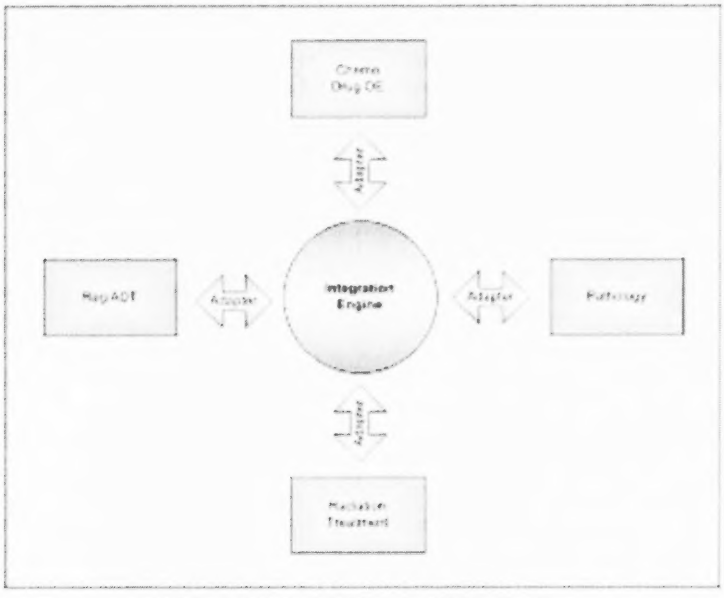

Figure 5.2. Intra-Hospital Integration

Inter-Hospital Integration

Cancer Care Ontario will need to obtain clinical, management and surveillance data from both ICP and non-ICP hospitals to support the initiatives outlined in the Information Management Strategy. The following sections outline the various components that make up the Integration Tier.

- **Network**

  Ideally the Smart Systems for Health (SSH) network will be leveraged for all network connectivity between sites. This provides the most secure and cost effective way to share data between the care providers, researchers and governing bodies that require data for surveillance, planning and funding purposes. SSH connections can be further secured with Access Control Lists (ACLs) on network devices to allow only pre-approved systems and applications to connect to each another. Also, Virtual Private Network (VPN) tunnels and Secure IP (IPSec) traffic can be used over the SSH network to encrypt and authenticate traffic.

- **Integration Engine**

  Integration (Interface) Engines will provide the majority of the back-end integration services for hospitals across the province. While Health Level Seven (HL7) message streams are the preferred message type,

other message types will be processed as needed. Integration Engines will also be used to pickup and process data extracts from the various patient care systems in the hospitals.

Integration Engines were developed to address the issues that arise when trying to do point-to-point integration, where new communication programs are developed between each pair of applications. Point-to-point integration is impractical as the number of interfaces required grows exponentially. This can be reduced to a linear increase through the use of Integration Engines. Integration Engines also speed development of interfaces by providing Adapters for popular communication protocols, thus requiring little or no coding, and providing message definitions for popular message types to facilitate message parsing.
A centralized farm of Integration Engines will be deployed at either CCO or a SSH Data Centre to provide the aforementioned services. Because of the speed of the SSH network, it is not foreseen that CCO will need to perform any message queuing at the remote hospital sites and an Integration Engine will not be deployed at a remote hospital if one is there already. In the case that an Integration Engine is not present at the hospital site or there is a specific need to provide message queuing or data transformation services, one could be placed on site.

- **Master Patient Index**
  The Master Patient Index (MPI) is a database used to assign a unique key for each person identified in the province. The MPI is populated with data from hospital Admission, Discharge, Transfer (ADT) systems across the province. The preferred method of obtaining this ADT data is via HL7 Minimum Lower Layer Protocol (MLLP) feeds, however, this is not required. The MPI is critical for the linkage of health information that is fragmented across the disparate regions, service providers and information systems in the province.

  A unique key is assigned to a person based on matching key identifiers with a high degree of accuracy. Identifiers could include OHIP number, name, date of birth and address. Generally linking occurs automatically according to rules defined in the linking algorithm. In cases where there is a "possible match" that the MPI cannot conclusively determine, the message is flagged for manual review by a trained health records professional.

  Once generated, this unique key can then be used to correlate and cross-reference computerized patient records and data from different health care organizations across the province, thus generating a truly longitudinal view of a patient's care. Also, encounter information obtained from ADT messages will be captured to provide further information to clinicians operating on the network.

  The benefits of the MPI are seen at both the Clinical Application and Data Tiers of the enterprise. For example, at the Clinical Application Tier, patient data from different sites can be found through a portal at a clinician's desktop. At the Data Tier, the key generated by the MPI can be used to link a tumour in the tumour bank to clinical data about the patient.

  The MPI will be deployed in a clustered environment at either CCO or at the SSH Data Centre.

- **Application Server**
  While the Integration Engine is responsible for back-end integration, the Application Server is responsible for front-end integration and Query Services resulting in integrated clinical desktops or a clinical portal. This is accomplished by passing patient context information in a query to the various participating systems and retrieving the results from that query. This service requires the MPI to provide these real-time lookups on the patient population.

The integration performed by the Application Server differs from the Interface Engine. While the Integration Engine provides data exchange and synchronization between the various clinical systems at all times automatically to support cross-referencing that is needed in the future, the Application Server only looks up data when it is asked. The Application Server will interface with the source data systems using a pre-built application/protocol adapter, a custom application/protocol adapter or through direct database access.

In addition to using the Application Server as a front-end integration engine, it can also be used as common application development platform to create robust, scalable solutions for the enterprise. It is foreseen that this infrastructure will also be used in the development of the Cancer Coalition Intranet/Extranet and in other custom application development projects (e.g. waitlist management and clinical trials systems).

As with the Integration Engines, a centralized farm of Application Servers will be deployed at the SSH Data Centre.

DATA TIER

While each system in the Clinical Application Tier maintains its own database, this tier represents the collection and aggregation of application data for the purposes of surveillance and monitoring initiatives, housing CCO-specific application data and housing CCO management data.

Operating at this layer are Online Transaction Processing (OLTP) Databases for CCO specific applications (for example a Clinical Trials Database), Online Analytical Processing Systems (OLAP) for Decision Support initiatives (for example an Enterprise Data Repository) and Directory Servers for mostly read only data (for example a user authentication database). Where possible, CCO should standardize on a single database vendor to provide these central database services.

At this tier most data will have been deterministically linked though the Master Patient Index to provide both a more accurate view of the data as well as providing linking in a real-time manner. It is also possible to generate de-identified subsets of data to support research initiatives. Identified and de-identified data sets will be used to support the following Information Management initiatives:

- Cancer Registry
- Referral and Waitlist Management
- Clinical Trials Database
- PIMS
- Research Databases
- Outcomes Tracking
- Data Repository
- Staging Information
- Screening Tracking
- Tumour Bank

A database presence will likely exist at both the CCO and SSH Data Centres to provide services for the aforementioned projects. OLTP and Directory Servers will likely reside at the SSH Data Centre to support operations across the province. Also operating at the SSH Data Centre may be data collection databases for Minimum Data Set data collected from the patient care systems located across Ontario. These collection databases could then be used periodically update the OLAP databases located at the CCO Data Centre (for example DTRACC databases).

Appendix 6: D-TRACC Overview

In 2000, the Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC) project was initiated. D-TRACC is intended to provide consistent management and planning information on cancer treatment, activity, quality and accessibility. The objectives of D-TRACC are:

- To track and report on access to cancer treatment and wait times in Ontario;
- To track and analyze the quality of cancer care provided to patients in Ontario;
- To improve human resources planning and funding by identifying demand, capacity, and constraints in the cancer treatment system;
- To provide outcome analysis by site, stage and treatment type;
- To identify constraints within the cancer system.

The D-TRACC project has been divided into three phases:

Phase I Systems Assessment - completed in June 2000
Phase II Functional Planning and System Design
Phase III System Implementation & Evaluation

In order to allow management to make timely, accurate decisions, D-TRACC requires data from a number of sources. The priority requirements for source data are:

- Pathology Reports, including pathologic stage – to be collected through PIMS;
- Systemic Treatment Data from RCCs, PMH and hospital HIS records;
- Radiation Treatment Data from RCCs and PMH;
- Surgical Treatment Data from PMH, hospital HIS records and OHIP billing records;
- Consultation Data from RCCs, PMH, hospital HIS records and OHIP billing records;
- Capacity Data from each cancer treatment facility;
- Cancer treatment guidelines data from PEBC;
- Mortality records from Vital Statistics.

Appendix 7: North Project

North Project 1: Establish a Cancer Information Infrastructure

The need for cancer services is especially critical in the North due to higher cancer trends compared to the rest of the province and the unique challenges of accessing health services in the North. Cancer services in Northern Ontario are currently characterized by a lack of integration between various providers, delayed detection of disease due to access issues, and less than optimal care.

It is proposed that Northern Ontario be the development site for the data integration infrastructure. Once the infrastructure has been developed and refined, it will be introduced into other regions in the province. Although the infrastructure focuses on cancer, hospitals will be able to use the system for other provincial and regional clinical programs (e.g., cardiac).

The integration infrastructure will support the secure exchange of clinical records between hospitals in real time. Integration of information will help improve clinical care especially since information on radiation, chemotherapy and cancer surgery will be linked, support the dissemination of practice guidelines and clinical trial protocols to front-line practitioners, support the proposed comprehensive treatment and outcomes database for cancer (D-TRACC), and will be invaluable for research. This initiative is critical for integrating cancer systems with hospital electronic health records and other clinical systems.

There are a wide range of benefits of the Cancer Information Integration Project. Generally, the project will improve access to integrated health care for Northern residents. Access to quality health care is an important component that contributes to the economic growth and prosperity of communities across Northern Ontario. The care experience for the cancer patient who requires different types of cancer care will become more integrated and coordinated. Since there will be real time interfacing with laboratory and other clinical systems, duplicate data entry will be reduced, resulting in safer and more efficient patient care.

This project will help attract and retain health care professionals in communities across the North by providing them with state-of-the-art information systems to help in patient care decisions. As well, the system will increase communications and the transfer of knowledge about cancer care across the North.

North Project 2: Enhance the Quality and Safety of Systemic Therapy

Providing quality cancer care to patients living in the remote communities of Northern Ontario is a challenge. The large distances patients need to travel to access care create emotional and financial hardships for patients and their families. Currently, northern patients requiring chemotherapy must travel to Sudbury or Thunder Bay for a portion of their care. Electronic linkages between the cancer centres in Sudbury and Thunder Bay and the local communities exist, but must be enhanced to improve integration and coordination of care.

A pan-northern oncology information system is to be implemented, in partnership with healthcare providers in the region, that builds on existing investments in health systems and network infrastructure. This system will see the delivery of chemotherapy CPOE rolled out to the approximately 40 peripheral and outreach cancer centres across Northern Ontario (see Figure 1). Linking these facilities will provide secure and appropriate access to clinical information when and where it is needed. Furthermore, by linking this system to provincial treatment guidelines and clinical decision support tools, knowledge of advances in cancer treatment will be more readily available to frontline patient care providers across the North. By allowing care to be provided closer to patients' homes, the need for patients to travel extensive distances will be reduced, leading to increased patient satisfaction reducing the burden on patients and their families.

Figure 1: Northeast and Northwest Chemotherapy Hospitals

Northeast Chemotherapy Hospitals	Northwest Chemotherapy Hospitals
- Anson General Hospital - Bingham Memorial Hospital - Chapleau General Hospital - Espanola General Hospital - Hôpital Régional Sudbury Regional Hospital - Huntsville District Memorial Hospital - Kirkland & District Hospital - Lady Minto Hospital - Mattawa General Hospital - North Algoma Health Organization - North Bay General Hospital - Northeastern Ontario Regional Cancer Centre - Sault Area Hospitals - Sensenbrenner Hospital - Smooth Rock Falls Hospital - South Muskoka Memorial Hospital - St. Joseph's General Hospital - St. Joseph's Health Centre - Temiskaming Hospital - Timmins & District Hospital - West Nipissing General Hospital - West Parry Sound Health Centre	- Atikokan General Hospital - Dryden District Health Centre - Fort Frances LaVerendrye Hospital - Geraldton District Hospital - Hearst Notre Dame Hospital - Hornepayne General Hospital - Kenora Lake of the Woods Hospital - Manitouwadge General Hospital - Marathon Wilson Memorial Hospital - Nipigon District Memorial Hospital - Northwestern Ontario Regional Cancer Centre - Red Lake MCM Hospital - Sioux Lookout Zone Hospital - Terrace Bay McCausland Hospital - Thunder Bay Regional Hospital

Appendix 8: List of Pathology Laboratories for PIMS Implementation

Note: Hospital pathology volumes are based on a 2 year average (1999-2001) and may not represent actual volumes and/or official hospital titles due to non-standard reporting mechanisms.

Facility	% of Total Lab Tests	Cumulative Total	PIMS Rollout Status
UHN- PRINCESS MARGARET HOSPITAL	6.2%	6.2%	Implementing
LONDON HEALTH SCIENCES HEALTH SCIENCES	5.7%	11.9%	
OTTAWA CIVIC HOSPITAL	4.1%	16.0%	
OTTAWA GENERAL HOSPITAL	3.8%	19.8%	
SUNNYBROOK HEALTH SCIENCE CENTRE	3.4%	23.1%	
KINGSTON HOSPITAL LABORATORY SERVICES	3.2%	26.4%	
LAKERIDGE HEALTH CORPORATION	3.1%	29.4%	Pilot
ST JOSEPHS HEALTH SERVICES ASSOC	2.6%	32.0%	
ST. JOSEPHS HEALTH CENTRE, SUDBURY	2.5%	34.5%	
ST JOSEPH'S HOSPITAL (Toronto)	2.5%	37.0%	
NORTH YORK GENERAL HOSPITAL	2.3%	39.3%	
ROYAL VICTORIA HOSPITAL	2.1%	41.5%	
MOUNT SINAI HOSPITAL	2.0%	43.5%	Implementing
PETERBOROUGH REGIONAL HEALTH CENTRE	1.9%	45.5%	
HUMBER RIVER REGIONAL HOSPITAL	1.9%	47.4%	
THE MISSISSAUGA HOSPITAL	1.9%	49.2%	
SCARBOROUGH GENERAL HOSPITAL	1.8%	51.0%	
ST MICHAEL'S HOSPITAL	1.7%	52.7%	
HAMILTON CIVIC HENDERSON GENERAL HOSP	1.7%	54.4%	
THE CREDIT VALLEY HOSPITAL	1.7%	56.1%	
PEEL MEMORIAL HOSPITAL	1.7%	57.7%	
THUNDER BAY REGIONAL HOSPITAL	1.6%	59.4%	
CENTENARY HEALTH CENTRE/ROUGE VALLEY	1.5%	60.8%	
HOTEL-DIEU GRACE HOSPITAL	1.4%	62.2%	
GRAND RIVER HOSPITAL CORPORATION	1.4%	63.6%	Contacted
CANADIAN MEDICAL LABORATORIES, MISS	1.3%	64.9%	
JOSEPH BRANT MEMORIAL HOSPITAL	1.3%	66.2%	
ST JOSEPH'S HEALTH CARE , LONDON	1.2%	67.4%	
MDS LABS	1.2%	68.7%	
SOUTHLAKE REGIONAL	1.2%	69.9%	
QUINTE HEALTH CORP	1.2%	71.1%	
GREY BRUCE HEALTH SERVICES	1.2%	72.3%	
TRILLIUM HEALTH CENTRE	1.2%	73.4%	
TORONTO EAST GENERAL ORTHOPAEDIC HOSP	1.1%	74.5%	
WILLIAM OSLER HEALTH CENTRE	1.1%	75.6%	
NORTH BAY GENERAL HOSPITAL	1.0%	76.6%	
SARNIA GENERAL HOSPITAL	1.0%	77.6%	
STRATFORD GENERAL HOSPITAL	1.0%	78.6%	
HOTEL DIEU HOSPITAL	1.0%	79.5%	

Appendix 8 List of Pathology Laboratories for PIMS Implementation (continued)

Facility	% of Total Lab Tests	Cumulative Total	PIMS Rollout Status
WOMEN'S COLLEGE HOSPITAL	0.9%	80.5%	
GUELPH GENERAL HOSPITAL	0.9%	81.4%	
TRAFALGER (HALTON HEALTH SERVICES)	0.9%	82.3%	
YORK CENTRAL HOSPITAL	0.8%	83.1%	
NIAGRA HEALTH SYSTEM GREATER NIAG.SITE	0.8%	83.9%	
MARKHAM STOUFFVILLE HOSPITAL	0.8%	84.8%	
SAULT AREA HOSPITALS, GENERAL	0.8%	85.5%	
WINDSOR REGIONAL HOSPITAL	0.8%	86.3%	
TIMMINS & DISTRICT GENERAL HOSPITAL	0.8%	87.1%	
HAMILTON CIVIC HAMILTON GENERAL HOSPITAL	0.7%	87.8%	
CAMBRIDGE MEMORIAL HOSPITAL	0.7%	88.5%	Pilot Installed
CHATHAM/KENT HEALTH ALLIANCE, ST. JOS.	0.7%	89.2%	
NIAGARA HEALTH SYSTEM COUNTY GEN SITE	0.7%	89.8%	
UROPATH DR. SRIGLEY'S PRIVATE PRACTICE R	0.6%	90.5%	
CHEDOKE MCMASTER MEDICAL CENTRE	0.6%	91.1%	
NIAGARA HEALTH SYSTEM GENERAL SITE	0.6%	91.7%	
ORILLIA SOLDIERS' MEMORIAL HOSPITAL	0.6%	92.3%	
ST THOMAS-ELGIN GENERAL HOSPITAL	0.6%	92.9%	
BRANT COMMUNITYHEALTH CARE SYSTEM	0.6%	93.6%	
PEMBROKE GENERAL HOSPITAL	0.6%	94.2%	
HOPITAL MONTFORT	0.6%	94.7%	
SCARBOROUGH HOSPITAL	0.6%	95.3%	
WOODSTOCK GENERAL HOSPITAL	0.5%	95.8%	
ROUGE VALLEY HEALTH SYSTEM	0.4%	96.2%	Negotiating
BROCKVILLE GENERAL HOSPITAL	0.4%	96.6%	
SOUTH MUSKOKA MEMORIAL HOSPITAL	0.4%	97.1%	
HOSPITAL FOR SICK CHILDREN	0.3%	97.4%	
ST. JOSEPHS HEALTH CENTRE, RELIG HOSP	0.3%	97.7%	
NORFOLK GENERAL HOSPITAL	0.3%	98.0%	
MEDICAL LABORATORIES OF WINDSOR	0.3%	98.2%	
GAMMA DYNACARE LABORATORY, BRAMPTON	0.2%	98.5%	Installed
CORNWALL GENERAL HOSPITAL	0.2%	98.7%	
DUFFERIN-CALEDON HEALTH CARE CORPORATION	0.2%	98.9%	
ROSS MEMORIAL HOSPITAL	0.2%	99.1%	
UNIVERSITY OF TORONTO OPHTHALMOLOGY LAB	0.1%	99.2%	
FLEMINGDON MEDICAL LABORATORY	0.1%	99.3%	
STRATHROY MIDDLESEX GENERAL HOSPITAL	0.1%	99.4%	
MED CHEM LABORATORY	0.1%	99.5%	
RIVERSIDE HOSPITAL	0.1%	99.6%	
WEST PARRY SOUND HEALTH CENTRE	0.1%	99.7%	
CHILDRENS HOSPITAL OF EASTERN ONTARIO	0.1%	99.8%	
MEMORIAL HOSPITAL BOWMANVILLE	0.1%	99.9%	
ST JOSEPH'S HOSPITAL	0.1%	99.9%	
SALVATION ARMY GRACE HOSPITAL	0.0418%	99.9897%	
TRENTON MEMORIAL HOSPITAL	0.0034%	99.9931%	
THE TORONTO HOSPITAL CORP.(TOR.GEN.)	0.0017%	99.9948%	
ALPHA LABS, TORONTO	0.0009%	99.9957%	
LONDON BIOCHEM REF. LAB.	0.0009%	99.9966%	
DUFFERIN AREA HOSPITAL	0.0004%	99.9970%	
MEAFORD GENERAL HOSPITAL	0.0004%	99.9974%	
THE GREY BRUCE REGIONAL HEALTH CENTRE	0.0004%	99.9978%	
BELLEVILLE GENERAL HOSPITAL-BANCROFT UN	0.0004%	99.9983%	
CHATHAM/KENT HEALTH ALLIANCE, PUBLIC CAM	0.0004%	99.9987%	
ST VINCENT DE PAUL HOSPITAL	0.0004%	99.9991%	
ATIKOKAN GENERAL HOSPITAL	0.0004%	99.9996%	
HALIBURTON HIGHLANDS HEALTH SERVICES COR	0.0004%	100.0000%	

Appendix 9: List of Hospitals Providing Chemotherapy

Note: The following hospitals submit requests for reimbursements from the New Drug Funding Program.

Hospital	City
Alexandra Marine and General Hospital	Goderich
Almonte General Hospital	Almonte
Anson General Hospital	Iroquois Falls
Arnprior and District Memorial Hospital	Arnprior
Baycrest Centre for Geriatric Care	Toronto
Bingham Memorial Hospital	Matheson
Blind River District Health Centre	Blind River
Brant Community Healthcare System	Brantford
Cambridge Memorial Hospital	Cambridge
Campbellford Memorial Hospital	Campbellford
Carleton Place and District Memorial Hospital	Carleton Place
Chatham-Kent Health Alliance	Chatham
Clinton Public Hospital	Clinton
Collingwood General and Marine Hospital	Collingwood
Cornwall General Hospital	Cornwall
Credit Valley Hospital	Mississauga
Deep Rivers' District Hospital	Deep Rivers
Dryden Regional Health Centre	Dryden
Dufferin-Caledon Health Care Corporation	Orangeville
Englehart District Hospital	Englehart
Espanola General Hospital	Espanola
Glengarry Memorial Hospital	Alexandria
Grand River Regional Hospital	Kitchener
Greater Niagara General Site, Niagara Health System	Niagar Falls
Grey Bruce Health Services	Owen Sound
Guelph General Hospital	Guelph
Haldimand War Memorial Hospital	Dunnville
Halton Healthcare Services	Oakville
Hamilton Health Sciences Centre - McMaster Site	
Hanover and District Hospital	Hanover
Hawkesbury and District General Hospital	Hawkesbury
Hotel Dieu Health Sciences Hospital	St.Catharines
Hotel Dieu Hospital	Cornwall
Humber River Regional Hospital	Toronto
Huntsville District Memorial Hospital	Huntsville
Huronia District Hospital	Midland
Joseph Brant Memorial Hospital	Burlington
Kemptville District Hospital	Kemptville
Kingston General Hospital	Kingston
Kirkland and District Hospital	Kirkland Lake
Lady Minto Hospital	Cochrane
Lake of the Woods District Hospital	Kenora
Lakedridge Health Oshawa	Oshawa
Lennox and Addington County General Hospital	Napanee
Listowel Memorial Hospital	Listowel
London Health Sciences Centre	London
Markham Stouffville Hospital	Markham
Meno Ya Win Health Centre (Sioux Lookout Zone)	Sioux Lookout

Appendix 9: List of Hospital Providing Chemotherapy (continued)

Hospital	City
Mount Sinai Hospital	Toronto
Niagara Health System, Welland Hospital Site	Welland
Norfolk General Hospital	Simcoe
North Bay General Hospital	North Bay
North York General Hospital	Toronto
Northumberland Health Care Corporation	Cobourg
Orillia Soldiers Memorial Hospital	Orillia
Ottawa Hospital, General Division	Ottawa
Pembroke General Hospital Incorporated	Pembroke
Perth and Smith Falls District Hospital	Smith Falls
Peterborough Regional Health Centre	Peterborough
Princess Margaret Hospital	Toronto
Quinte Healthcare Corporation	Belleville
Renfrew Victoria Hospital	Renfrew
Riverside Healthcare	Fort Frances
Ross Memorial Hospital	Lindsay
Rouge Valley Health System	Scarborough
Royal Victoria Hospital	Barrie
Sarnia General Hospital	Sarnia
Sault Area Hospitals	Sault Ste. Marie
Scarborough Hospital	Scarborough
SCO Health Services	Ottawa
Sensenbrenner Hospital	Kapuskasing
Smooth Rock Falls Hospital	Smooth Rock Falls
South Bruce Grey Health Centre	Kincardine
Southlake Regional Health Centre	Newmarket
St. Joseph's General Hospital Elliot Lake	Elliot Lake
St. Vincent de Paul Hospital Site	Brockville
St.Joseph's Toronto	Toronto
St.Mary's General Hospital	Kitchener
St.Michael's Hospital	Toronto
St.Thomas-Elgin General Hospital	St.Thomas
Stratford General Hospital	Stratford
Sudbury Regional Hospital	Sudbury
Sunnybrook and Women's College Health Sciences Centre	Toronto
Temiskaming Hospital	New Liskeard
Thunder Bay Regional Hospital	Thunder Bay
Timmins and District Hospital	Timmins
Toronto East General Hospital	Toronto
Trillium Health Centre	Mississauga
University Health Network - Princess Margaret Hospital	Toronto
West Lincoln Memorial Hospital	Grimsby
West Parry Sound Health Centre	Parry Sound
William Osler Health Centre	Brampton
Winchester District Memorial Hospital	Winchester
Windsor Regional Hospital	Windsor
Wingham and District Hospital	Wingham
Woodstock General Hospital	Woodstock
York Central Hospital	Richmond Hill

Appendix 10: Key Potential Sources of Funds

D-TRACC
In 2000, the MOHLTC initiated the Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC) project to develop a management and planning information system for cancer treatment in Ontario. D-TRACC is expected to improve management information resulting in earlier recognition of pending constraints in the system and the development of mitigation strategies, identification of best practices and high treatment quality and increased efficiency in cancer service delivery. The MOHLTC has given CCO the mandate for ongoing operation of the D-TRACC system. To date, the MOHLTC has provided an initial allocation of $17.5M over a number of years.

Cancer Care Ontario
Cancer Care Ontario (CCO) was created in April 1997. It is an operational service agency of the MOHLTC, is governed by the Cancer Act, and operates within the context of a Memorandum of Understanding with the MOHLTC (November 8, 1999). CCO has its roots in the Ontario Cancer Treatment and Research Foundation (OCTRF).

The vision of CCO is to lessen the burden of cancer in Ontario by ensuring that all residents have timely, equitable access to an integrated system of excellent co-ordinated and efficient programs in prevention, early detection, treatment, education and research.

In 2000/01, CCO had revenues of $284.4 million of which $244 came from the MOH. Other sources of funds included private donations, investment income, research grants, other grants, and other income. As a proportion of the provincial budget spent on cancer services, CCO governs and manages less than 20% of all services related to cancer assessment, treatment and follow-up.

Ontario Cancer Research Network
The Ontario Cancer Research Network (OCRN) is a not-for profit organization, established through two grants totaling $100 million over four years from the Ministry of Enterprise, Opportunity and Innovation to enhance translational cancer research in Ontario. Translational research refers to the laboratory and clinical testing needed to transform promising discoveries into new approaches and products that can prevent, control, diagnose, treat and ultimately cure cancer. Through its support of programs in basic and clinical research, infrastructure enhancement, information and communication, the OCRN hopes to accelerate the development of promising new cancer therapies, ultimately bringing new and innovative treatments to patients sooner.

Northern Ontario Heritage Fund
The Northern Ontario Heritage Fund Corporation (NOHFC) assists northern communities to generate short and long-term employment important to their economic viability and the quality of life. The Fund has been redesigned to reflect the changing nature of the North and the world economy.

In the Spring 2000 Budget, the Ontario Government renewed the mandate for the NOHFC by increasing its funding to $300 million over five years, with annual funding doubling to $60 million to support northern communities. Since October 1996, the Ontario government has contributed more than $330 million to some 970 NOHFC projects, generating an additional $812 million from project partners. These projects have created an estimated 14,000 jobs in Northern Ontario. The use of these funds will continue to level the playing field to ensure that northerners have the same opportunities as the rest of Ontario.

Canada Health Infoway Inc.

Canada Health Infoway (Infoway) is an independent not-for-profit corporation whose mission is to foster and accelerate the development of interoperable electronic health systems across Canada. These systems will improve the health sector by providing citizens and their health care providers timely and secure access to the information required for health care. Infoway reports to its Members, who are the Deputy Ministers of Health of the federal, provincial and territorial governments. The Government of Canada has committed $500 million to Infoway.

Infoway will build on existing initiatives and best practices, focusing on interoperability and connectivity, and work collaboratively with partners ranging from governments and providers to patient groups, technology experts and information technology companies to promote and facilitate the development of interoperable Electronic Health Record solutions on a pan-Canadian basis. Infoway will be a proactive investor with its partners and project enablers.

Ministry of Health and Long Term Care

The Ministry of Health and Long Term Care (MOHLTC) is responsible for administering the health care system and providing services to the Ontario public through such programs as health insurance, drug benefits, assistive devices, care for the mentally ill, long-term care, home care, community and public health, and health promotion and disease prevention. It also regulates hospitals and nursing homes, operates psychiatric hospitals and medical laboratories, and co-ordinates emergency health services.

Appendix 11: Cancer System Priorities & Information Initiatives (Retreat Package)

CANCER SYSTEM PRIORITY BRIEFINGS

1. **Improving Access Management for Cancer Care Services**
2. **Integrating Service Delivery**
3. **Supporting Evidence-Based Care and Improving Patient Safety**
4. **Monitoring Outcomes and Targeting Areas for Quality Improvement**
5. **Increasing Early Detection of Cancer Through Screening**
6. **Preventing Cancer Through Reduced Exposure to Known Risks**
7. **Improving Cancer System Planning**
8. **Enhancing Infrastructure for Cancer Research**

IMPROVING ACCESS MANAGEMENT FOR CANCER CARE SERVICES

The Cancer Services Implementation Committee (CSIC) identified 'timely, equitable and appropriate access to comprehensive cancer services' as a criterion to be used to guide deliberations to meet the Committee's vision for cancer services. As cancer services are provided by many care providers who represent a wide variety of professional groups in Ontario, coordinated access is critical to ensure that the right services are provided when and where they are needed.

There are many opportunities to improve access to cancer services:

- *Access to radiation services can continue to improve.* Currently, waiting lists are relatively long and rates of radiation treatment (percentage of incident cases treated with radiation therapy) are low in comparison to other jurisdictions. The demand for radiation services is expected to climb with higher treatment rates and increased treatment capacity;

- *Improved access to diagnostic tests will result in more timely diagnosis.* Imaging modalities have continued to evolve, become more efficient and improved diagnostic capabilities. However, competition for access from patients with other diagnoses compromises timely access. Cancer patients are waiting in line for diagnostic tests behind other patients with less life threatening or time sensitive problems. This causes delays in diagnosis and treatment;

- *Lengthy waiting times to a diagnosis lead to worse prognostic indicators.* Many women with screen-detected abnormalities experience lengthy waiting times to get to a diagnosis. Not only is this a time of anxiety and worry for women who have been apparently healthy, but an association has been shown between lengthy waiting times to a diagnosis of breast cancer and worse prognostic indicators;

- *Surgical waiting lists are not tracked consistently so reliable provincial data that identifies access problem is not available.* While anecdotal evidence suggests that there are significant access problems for some surgical specialties in some parts of the province, lack of concrete information and supporting systems makes arriving at definitive conclusions difficult; and

- *Supportive care services are a major determinant of patient satisfaction.* Patients and providers are not aware of what supportive care services are available. Access to these services varies across the province with regard to availability, visibility and accessibility of services and expertise.

A variety of approaches to improving access to services have been proposed, including:

- Define and implement standard definitions for clinical activity and implement the collection of province-wide data to monitor the supply of services;

- Implement a province-wide referral management system to support effective prioritizing of patients according to patient acuity and clinical need, to manage wait lists and to track demand for cancer services. Similar to the Cardiac Care Network of Ontario, this system would collect the necessary information (e.g., staging information) to determine patient priority and to interpret the clinical significance of delays in diagnosis and treatment;

- Establish activity-based funding to support the volumes necessary to meet increasing demand for services;

- Increase patient and provider awareness of supportive care services available and improve physicians' ability to access evidenced-based guidelines that support consistent, high quality practice;

- Increase access to cancer prevention services, programs and to the protection afforded by public health policies;

- Establish guidelines for cancer diagnosis that define maximum wait times for diagnostic services. Track time to diagnosis for cancer patients to determine if guidelines are being met; and

- Provide cancer patients with priority access to diagnostic services.

Various challenges include:

- There are a large number of providers involved in cancer care making it difficult to implement province-wide programs. Furthermore, change management is rendered difficult because there are so many competing issues vying for the attention of providers and system managers;

- There is limited availability of the required clinical and population health professionals necessary to improve access; and

- Evidence-based standards for diagnostic and treatment wait times are difficult to determine.

INTEGRATING SERVICE DELIVERY

Delivery of cancer services is fragmented across health care organizations (host hospitals, other hospitals, regional cancer centres, other organizations and community-based providers). Fragmentation results in poorly coordinated patient care and costly duplication of administrative functions between cancer centres and host hospitals. Several factors contribute to fragmentation:

- *Manual referral mechanisms used by a multitude of providers during a single episode of disease impacts on care coordination.* For example, a patient can wait in line for each different treatment modality during a single episode of illness. This occurs because diagnostic testing, surgery, radiation and systemic therapy are often provided by different organizations, each with its own approach to scheduling and wait list management;

- *Poor, slow or absent transfer of health records and diagnostic images* between providers results in diagnostic repetition, delays, increased costs, patient discomfort and sub-optimal support for clinical decision-making;

- *Lack of regional cancer centre integration with host hospitals results in duplication of efforts* that could be more effective and efficient if provided as a shared or common service. Examples include administrative functions, information systems, patient registration and payroll; and

- *Separate organizational structures for different care modalities offer little incentive for integration and communication* (e.g., RCCs for systemic therapy or radiation, hospitals for surgery, community agencies for supportive care, multiple agencies delivering preventive programs below threshold dose yet in competition with each other).

Currently, CCO is the direct provider of services for only 20% of cancer treatment spending. To be effective, this strategy must address access and quality for the delivery of all cancer services in Ontario. To achieve this, CCO has several mechanisms:

- Direct Service Delivery – CCO has direct line management responsibility for care delivery to ensure services conform to mandate.

- Funding – CCO can use funding programs (such as the New Drug Funding Program) to help motivate the achievement of access, volume and quality goals.

- Advisory – CCO can collect and analyze information to plan improvement strategies and advise both government and providers on changes necessary to achieve quality and access objectives.

Due to local significant variations, different approaches to integration are being contemplated for different regions of the province. Although the integration model and CCO's role as a direct provider of services may differ somewhat in different regions of the province, access to comprehensive, integrated high quality cancer services must be provided to all Ontarians. Hence, a set of performance standards for access and quality will be established to form the basis for care delivery for all providers including CCO-operated programs. Where CCO is not the direct service provider, CCO will require a contractual framework tied to funding that will support the achievement of these standards by other service providers. This contract would specify CCO's commitment to funding and the corresponding responsibilities of the service provider.

SUPPORTING EVIDENCE-BASED CARE & IMPROVING PATIENT SAFETY

The Program in Evidence-Based Care (PEBC), established in 1997, uses research results to influence practice by developing evidence-based clinical practice guidelines. Teams made up of health care providers, community representatives and researchers select and review the best and most relevant studies, synthesize relevant research information, obtain input from specialists and make recommendations for cancer care. The groups also develop evidence summaries on clinical topics where there is insufficient evidence to develop a practice guideline. Guidelines and summaries are distributed to clinicians and planners.

Several opportunities exist to support evidence-based care and improve patient safety in Ontario:

- *Tools need to enable systematic, comprehensive tracking of practice with evidence.* Although the PEBC has approximately 80 guidelines available on its website, the degree to which these are followed is unclear. Tracking and reporting back to physicians their practice patterns relative to guidelines would substantially improve awareness of guidelines in the province. While quite a bit of work has been done, the challenge is tracking practice in a systematic and comprehensive manner;

- *There is a high rate of Computerized Physician Order Entry (CPOE) for systemic therapy but limited use of clinical decision support tools.* 50% of all systemic therapy orders in the province are entered by physicians directly into computer systems (mostly at CCO regional cancer centres). There is strong evidence to suggest that physician order entry of drug orders can significantly reduce error rates. Clinical alerts can be provided at the time of order entry to substantially improve clinical decisions and outcomes. CPOE for systemic therapy could be implemented throughout the rest of the province. Clinical alerts, designed to reduce clinical errors and increase the influence of evidence on clinical decision-making, would improve safety and patient outcomes;

- *Developing data for Ontario that links patient information (e.g. site and stage) with clinical orders and outcomes would identify significant opportunities to improve outcomes.* Emerging evidence suggests that significant practice variation exists. Capturing clinical stage information is required to identify opportunities for improving practice and patient outcomes; and

- *The scope of guidelines can be extended to cover more of the cancer care continuum.* With more resources dedicated to developing guidelines and implementing Clinical Decision Support rules, the emphasis on quality and consistent care supported by evidence can be extended to other areas of cancer care.

All care programs should be designed to help caregivers provide the best quality care and prevent clinical errors. To support evidence-based care and improve patient safety, there is a need to:

- More actively disseminate guidelines and track consistency of practice with evidence;

- Emphasize the introduction of physician order entry directly into computer systems in all health care facilities;

- Develop notification mechanisms that alert physicians when a guideline applies to a particular patient;

- Track outcomes and modify clinical tools in response to identified opportunities for quality improvement; and

- Collect staging information to determine when specific guidelines apply.

Various challenges exist:

- Presently, it is difficult to ascertain the degree to which guidelines are being applied across the province. Barrier exist to systematically evaluate the correspondence between practice and evidence;

- Without the support of the hospital community, it would be difficult to increase the rate of CPOE outside of CCO; and

- Little data exist that links patient information with clinical orders and outcomes on a provincial level. Insufficient opportunity to link patient information, clinical orders, outcomes and guideline recommendations. The lack of information standards combined with the wide array of different vendor applications across Ontario further complicates the data collection process

MONITORING OUTCOMES & TARGETING AREAS FOR QUALITY IMPROVEMENT

In recent years, health services research has revealed marked variability in practice patterns and outcomes between providers, institutions and geographic regions. Furthermore, there are often marked differences between outcomes achieved in clinical trials and those seen routinely in clinical practice. Although the causes of this variability are not completely understood, a number of sources of sub-optimal outcomes have been identified including:

- *Clinical errors*, resulting in sub-optimal therapy that inadvertently harms the patient;
- *Lack of application of current evidence-based treatment*;
- *Low patient volumes* making it difficult to maintain a standard of practice consistent with optimal outcomes; and
- *Access problems* that lead to selection of sub-optimal therapies or clinically relevant treatment delays.

As awareness of these factors has emerged in recent years, it has become clear that major improvements in patient outcomes are possible through the implementation of strategies designed to mitigate these factors. An excellent example is the dramatic variability in postoperative mortality seen across Ontario for pancreatic cancer. A strategy that provided surgeons and hospitals with performance benchmarks that compared their surgical outcomes to those of others in the province has resulted in major shifts in practice patterns. Many surgeons who were performing small numbers of procedures are now opting to refer patients to larger volume centres. This approach will be expanded to include many other aspects of the cancer system.

Monitoring outcomes and targeting areas for quality improvements has stimulated interest in provincial databases that include clinical information such as tumour site, stage, treatment received and outcome measures. Capturing this data accurately and in a timely fashion is a major challenge that is necessary to identify opportunities for improved outcomes and to track changes over time to see if improvements have been achieved.

To satisfy the need to monitor outcomes and increase the quality of the cancer system several steps need to be taken:

- Establish a Quality Council responsible for setting standards for caner service delivery, monitoring and reporting on performance of services against standards and advising stakeholders of areas where the quality and access to services can be improved.
- Enhance the provincial systems to collect and report clinical and outcome data for all treatment modalities. This requires all providers of these services to submit to a central database standardized information including tumour site, stage, treatment administered and outcomes;
- Understand from a patient perspective the quality of care they feel they have received and include patient preferences in clinical decision-making;

- Develop approaches to report wait times and outcomes performance against provincial comparators, back to providers to enable them to identify opportunities for modifying practice to improve outcomes; and

- Develop clinical standards and provide the education necessary for surgeons, physicians and hospitals to achieve optimal clinical results. This includes suggesting minimal annual volume levels necessary for good outcomes.

Various challenges include:

- Defining and standardizing the collection of the information necessary to enable accurate and timely reporting of outcomes;

- Dissemination of clinical and system outcome information to decision makers; and

- Overcoming a fear of individual blame to create a culture of continuous improvement in system performance and patient safety.

INCREASING EARLY DETECTION OF CANCER THROUGH SCREENING

Screening involves regularly examining average-risk individuals within a certain population group for the signs or symptoms of a disease (e.g., cervical cancer screening, Ontario Breast Screening Program). Screening programs result in early detection of cancer, leading to more timely treatment and better outcomes. Currently there is a limited number of cancer sites for which there is well-established evidence to support population-based screening (breast, cervix, colorectal). However, evidence is emerging for a number of other screening modalities, including the screening of precursors and markers of predisposition. Thus early detection will likely become more prominent as a strategy in cancer control in the future.

Opportunities exist to improve early detection of cancer by increasing participation in effective screening activities and evaluating the quality and outcomes of screening. Effective deployment of screening programs requires good information on participation rates andprogram outcomes.

There are opportunities to improve the planning and evaluation of screening activities:

- *Track screening that is provided outside of CCO-organized programs.* CCO runs organized screening programs for breast and cervical cancer. The amount of screening occurring outside of CCO programs is unknown (e.g. physicians' offices, hospitals and community clinics). There is likely a considerable opportunity to improve outcomes through a more unified and comprehensive approach to measurement of screening activity throughout the province;

- *Collect stage information routinely at diagnosis.* Capture of stage information at first detection would help in the design of new screening programs and evaluation of program effectiveness. At present, staging information is recorded upon presentation to CCO regional cancer centres. This information is not collected from other providers in the system. The OBSP stages all of the cancers diagnosed in its clients by retrieving clinical and pathological information from several sources;

- *Determine if there is consistency of practice in screening.* The establishment and dissemination of evidence-based guidelines will support consistency of practice with evidence resulting in quality care. Screening should occur at the recommended screening frequency in individuals who meet established eligibility criteria. Without access to population screening and outcome data, quality of cancer screening cannot be determined;

- *Assist physicians to be aware of new screening guidelines.* In this emerging era of evidence-based practice, it is difficult for physicians to keep abreast of all of the changes in best practice as they occur (whether they relate to cancer or the myriad of other diseases physicians treat). New screening guidelines compete for a physician's attention with all the other new treatment approaches that emerge on a regular basis. Incorporation of clinical rules into electronic health records would enable systems to identify patients that should receive screening services consistent with the most up-to-date guidelines; and

- *Assist providers to identify and communicate with people who have not had the benefit of screening consistent with screening protocols.* In the absence of integrated and comprehensive electronic health records, it is a very laborious, manual process to identify patients that meet screening criteria but have not yet been screened.

Increasing the proportion of Ontarians who benefit from effective screening activities presents a number of challenges:

- A high proportion of screening activity takes place at the primary care level. The absence of electronic patient record systems and marked fragmentation of service delivery will make it difficult to track activity and disseminate new guidelines and procedures;

- The public must be informed of both the need for screening and how to access the screening system. Unfortunately, there have been several high profile examples of controversy in the press about optimal approaches to screening. Unfortunately, this has confused many about the current state of screening in the province; and

- Once appropriate screening guidelines have been issued and disseminated to practitioners and the target population, Cancer Care Ontario will be required to monitor and assess effectiveness of screening in Ontario in order to advise the Government on how to improve early detection.

PREVENTING CANCER THROUGH REDUCED EXPOSURE TO KNOWN RISKS

At the population level, cancer prevention involves reducing or eliminating exposure to known causes of cancer and thereby reducing the burden of avoidable premature disease. Scientific evidence is unequivocal that tobacco use causes cancer. Other risk factors include: inadequate consumption of vegetables and fruit, physical inactivity, unhealthy body weight and obesity, alcohol consumption, exposure to sunlight, occupational carcinogens, and infectious agents (e.g., Hepatitis C, HPV).

The need to increase the level of cancer prevention and reduce exposure to known risks is increasingly a priority of the cancer system. It has been proven that limiting the exposure to known causes of cancer such as tobacco will reduce avoidable disease burden.

There are opportunities to strengthen prevention efforts:

- *Provide the population with easy and convenient access to high quality relevant cancer prevention information.* Available technologies and emerging prevention techniques should be used to convey this information in a timely and effective manner. One mechanism is the Internet - accessing health-related information is one of the leading uses of the Internet by the general public.
- *Implement proven population-based interventions.* It has been estimated that tobacco use could be cut by more than 50% among adults and children within 10 years if proven technology were implemented on a systemic, comprehensive basis. The Ontario Government has supported these developments in the past and has expressed interest to enhance prevention.
- *Put a system in place to measure provincial prevention efforts.* Systems are required to continually assess capacity of the system to deliver effective interventions, population exposure to interventions (program, media and policy), identify the prevalence of risk factors and track changes toward the attainment of strategic population-based objectives.
- *Identify at-risk individuals through the uses of new data sources.* Once these individuals have been identified, prevention efforts can be targeted specifically at these groups.

IMPROVING CANCER SYSTEM PLANNING

Effective cancer system planning is essential to anticipate future requirements for cancer care and to manage the ystem successfully so that service delivery objectives can be met. Improving cancer system planning is dependent on monitoring and managing a number of complex requirements and constraints. For example, demand for services is increasing due to an aging population, new technology is continually enhancing and changing treatment options, and specialized expertise is becoming more difficult to source due to a lack of skilled professionals. Data on supply and demand must be collected, analyzed and projected as a basis for cancer system planning.

There are opportunities to improve cancer system planning:

- *Implementing an inter-institutional, provincial-based HR planning system* to provide necessary data to project the future needs and supply of specialized clinical professionals;
- *Expanding activity-based funding mechanisms* to other parts of the cancer system to make the supply of services more responsive to changes in demand;
- *Enhancing technology assessment and the development of clinical practice guidelines* to provide the capability to project demand for existing clinical services and new therapeutic approaches;
- Capturing more *comprehensive staging information* to permit improved surveillance and outcomes evaluation;
- *Tracking wait lists* to identify pressure points in the cancer system;
- Collecting *comprehensive systemic drug data*; and
- Collecting information to predict the costs of implementing new or amended practice guidelines and the relative impact on clinical practice.

ENHANCING INFRASTRUCTURE FOR CANCER RESEARCH

Ontario has an international reputation for its cancer research that includes basic, translational and health services research. Research in Ontario is conducted by investigators affiliated with a wide range of organisations, including universities, affiliated teaching hospitals, PMH/OCI, CCO, ICES and private industry.

Research funding comes from a number of sources. The majority of funds are awarded by international, national, provincial and local agencies after a highly competitive review process. Funds are also obtained from industry, particularly for clinical trials. CCO provides very limited direct funding for research from its operating budget. It does, however, play an important coordinating role across academic health science centres.

Ontario established the Ontario Cancer Research Network (OCRN) in December 2000. OCRN has a budget of $100 million to be spent over the next three years on cancer research infrastructure development in Ontario. The vision of the Network is for Ontario to be a world leader in translational cancer research. The goals of the Network are to: 1) provide infrastructure so that the number of patients entering clinical trials in Ontario will double over three years; 2) provide research funds to speed translation of research into new therapies; 3) create an information network linking cancer centres, researchers and patients; and 4) create a tumour bank network, and 5) support population based studies. The success of the Network depends on developing partnerships and cooperation among providers and investigators throughout the entire cancer care community.

A major national effort is underway to create and implement a cancer control strategy that includes a significant research component. The strategy was developed by Health Canada, the National Cancer Institute of Canada, the Canadian Institutes of Health Research and the Canadian Association of Provincial Cancer Agencies.

Research efforts are being directed increasingly at studying the specific genetic profiles that control the aggressiveness of certain tumours in patients, their likely clinical course, sensitivity to radiotherapy, or susceptibility to drug treatment. Ultimately, it is hoped that a genetic profile can be obtained for each patient's tumour cells so that therapy can be individualized. This kind of research is very costly and currently is best carried out by well-funded, large groups or consortia of groups of investigators. It is unlikely, although not impossible, that small research units will make much progress in cancer gene research. Units unable to concentrate the critical mass of people, machinery and dollars are more likely to contribute in other important areas such as clinical trials.

A major determinant of success in genomic research related to cancer is the volume of patients available for investigation. Linkage of a patient's genetic "bio-file" with their clinical course is required to determine the clinical significance of each genotype. Given the large number of genes in the human genome and the multifactorial nature of genetic expression, it takes large numbers of patients in a single database to correlate genotype with clinical behaviour. This will require the development of a fully-linked comprehensive database for cancer research that includes clinical records, the genetic bio-file and linkage to tissue samples in a tumour bank. Ontario has a unique opportunity to establish a single standard data structure to capture this information for the entire cancer population. Hence, coordinating these efforts across the province is essential to achieve our full research potential.

A key element in this agenda is the need for standardization of the genetic bio-file across the province. If this standard bio-file assay is performed on all tissues stored in tumour banks and linked to the patient's clinical record, researchers could access this virtual tumour bank for conducting many studies rather than needing to access tissue samples directly. For this strategy to be effective, researchers across the province must agree on the definition of the gene chip used to create the genetic expression profiles that go into this database. If this

is achieved, Ontario will have a research resource unique in the world that will attract funding and investigators from around the globe.

These linked databases are also necessary for translation of research results into clinical practice. Once the relationships between genotype and clinical behaviour are understood, clinicians will need access to the patient's genetic bio-file to optimize their treatment program. Hence, it is essential that the information infrastructure be designed to address the requirements of the research community and practitioners. A close partnership between researchers and clinicians must be fostered, as both must contribute to the successful implementation of this approach. Clinicians must obtain patient consent to participate in tumour banks and to contribute their bio-file to these databases. Researchers must establish the relationships between tissue genotype and optimal therapy for use at the bedside. The information infrastructure is necessary to allow this partnership to operate effectively.

In addition, it is essential new technologies for the primary prevention and screening of cancer be developed, evaluated and disseminated. A science of knowledge translation, based on socio-behavioural models of diffusion of innovations and organizational change, needs attention if new technology will be implemented widely, effectively and efficiently. The information infrastructure must support such research and development.

The information infrastructure in place across the province will also be a key determinant of clinical trial enrolment as well. Critical to improving enrolment rates is making clinicians aware of clinical trials with enrolment criteria that match their patients' clinical status. As the number of clinical trials increase, it will be difficult to keep physicians aware of all the trials that are enrolling patients at any point in time. Centralized databases being developed for staging and outcome analysis can be used to identify potential candidates for clinical trials if they are collected and reported in real time. The PIMS project, designed to capture pathology information and report it to the Ontario Cancer Registry in real time, is a good example. This information could be used to match site and histological stage information to clinical trial enrolment criteria. The physician responsible for care of that patient could be informed of protocols that might be of interest to their patient.

There are opportunities to enhance infrastructure for cancer research:

- Agree on a standard genetic bio-file across the province;
- Engage clinicians outside academic centres to increase clinical trial enrolment;
- Address privacy concerns as large databases with genetic profiles are compiled; and
- Standardize the collection of clinical profiles for linkage with genetic profile.

APPENDIX 11

CANCER INFORMATION MANAGEMENT INITIATIVE BRIEFINGS

1. **Referral Management & Wait List Tracking System**
2. **Pathology Information Management System (PIMS)**
3. **Capturing Clinical Stage Information**
4. **Surgical Activity Tracking**
5. **Systemic Therapy Management System**
6. **Radiation Therapy Management System**
7. **Regional EHR Initiatives**
8. **Clinical Trials Enrollment and Management**
9. **Clinical Databases to Support Tumour Banking**
10. **Provincial Human Resource Planning System**
11. **Screening Tracking System**
12. **Guideline Use Tracking System**
13. **Enhancement to the Ontario Cancer Registry**

REFERRAL MANAGEMENT & WAIT LIST TRACKING SYSTEM

Cancer care is fragmented and lacks coordination. Comprehensive information on access to cancer treatment is not available since current systems do not capture and aggregate information for all Ontario cancer patients. This lack of information makes it difficult to manage referrals for cancer care and to track waiting times. This situation is becoming more urgent as the incidence of cancer rises (3% annually), and as patients live longer with the disease resulting in a rise in service demand (7% annually).

A system for referral management and wait list tracking would allow users to:

- Enter referrals into the system for all patients including tumour site and stage information;
- Prioritize cases by severity and urgency class; and
- Track how long a patient waits from the time of posting to the system to the time of service delivery for each service type.

With the resulting database, it would be possible to assess whether new initiatives result in desired outcomes such as improved quality of service delivery, improved access or reduced wait times. Reports to assist with planning and management would also be available. These reports would enable managers to:

- Obtain critical information to identify service delivery barriers (e.g., shortage of professionals, bottlenecks in access to medical devices) so mitigation strategies can be developed and implemented more quickly;
- Track access to cancer treatment and assess the quality of care provided;
- Provide key information on system demands and supply to support capacity planning; and
- Provide necessary information to improve human resource planning and funding by identifying demands for, capacity of and cost constraints in the cancer system.

The Cancer Services Implementation Committee examined a number of service delivery models and noted particular interest in the Cardiac Care Network of Ontario (CCN) approach. CCN is a partnership of health professionals, hospitals and government that focuses on appropriate and timely access to adult cardiac services by patients and their physicians.

A key role of CCN is to coordinate the provision of advanced adult cardiac services province-wide. To accomplish this, a computerized referral management and wait list tracking system was developed to facilitate and monitor access to services by patients and their physicians. This system is also instrumental at providing extensive statistics on access to services that are available in a timely fashion via the Internet. Since its development in 1990, the registry has been expanded to include a number of additional cardiac treatments. CCN has had tremendous success in improving the quality, efficiency, access and equitable delivery of cardiac services in Ontario.

A key challenge to efficient referral and wait list management is the need to focus on all treatment modalities rather than a single modality. For example, the wait list tracking system should track a patient as they move from surgery to radiation rather than recording these as independent events. Commercially available software does not handle referral and wait list management well. Hence, any large-scale effort to implement this type of functionality across the province would likely require custom software development.

APPENDIX 11

Developing a referral management and wait list tracking system will:

- Improve access management for cancer care services;
- Support integration of service delivery;
- Facilitate monitoring of outcomes and targeting areas for improvement; and
- Improve system planning.

PATHOLOGY INFORMATION MANAGEMENT SYSTEM (PIMS)

The pathology report contains a number of key pieces of information that are essential for treatment planning and outcome analysis. In most cases, the report contains the initial diagnosis of a patient's cancer and includes disease site and histological stage data at the time of diagnosis. Timely collection of complete and accurate pathology information is critical in supporting the Ontario Cancer Registry (OCR) and Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC) initiatives.

In 2000, the Ministry of Health and Long-Term Care initiated the D-TRACC project to implement a flexible and cost effective system to provide comprehensive planning and management information for cancer treatment activity, quality and accessibility. D-TRACC will support the earlier recognition of pending constraints in the system and support development of mitigation strategies, identification of best practices and high treatment quality and increase efficiency in cancer service delivery.

Currently, over 85,000 paper reports are submitted annually by 85 laboratories to the OCR. Staff are responsible for manually entering this information into a system for integration into the OCR. In 2001/2002, the Surveillance Unit at CCO developed a custom Pathology Information Management System (PIMS) in conjunction with a vendor to allow labs to submit relevant information electronically to the OCR in a more timely and efficient way. This approach replaces manually intensive tasks associated with searching, sorting and sending paper pathology reports to the OCR. These tasks are labour-intensive, costly and slow. PIMS has been successfully piloted with 3 laboratories in Ontario. Evaluation of the pilot showed an improvement in the timeliness, standardization and comprehensiveness of the data.

To realize the full potential of PIMS, the following objectives should be undertaken:

- All hospital pathology systems are to be interfaced to the OCR to provide electronic, near-real-time reporting of the histological results thereby reducing manual workload associated with submitting or reentering results and providing a comprehensive and accurate information source;
- Develop a database and search tool to allow clinicians to access information on groups of patients with similar characteristics to support research and learning initiatives and requirements (e.g., tumour bank);
- Use pathology reports to trigger the dissemination of appropriate current practice guidelines or clinical trials protocols;
- Link relevant clinical databases to ensure pathology reports are available to clinicians when patients are transferred from one facility to another; and
- Collect valuable information on the care, outcomes and occurrence of cancer to support research and planning.

Successful expansion of the PIMS initiative will:

- Support evidence-based care and improve patient safety;
- *Facilitate monitoring of outcomes and targeting areas for improvement;*
- Increase early detection of cancer through screening;
- Improve system planning; and
- Enhance infrastructure for cancer research.

CAPTURING CLINICAL STAGE INFORMATION

The electronic capture of clinical stage information is important for interpreting outcomes, planning, cancer surveillance, making treatment decisions, and monitoring the applicability of guidelines. Accessing clinical stage information for all of these uses would have a profound effect on the quality of care delivered in the cancer system.

Comprehensive staging information requires the collection of histological and clinical stage from all providers. Although implementation of the PIMS initiative will enable consistent and timely capture of histological stage, comprehensive staging information also requires clinical staging data from diagnostic tests and physical examination.

A comprehensive system that captures all stage information will:

- Collect clinical stage information for all modalities of care. The system can be expanded to include all healthcare facilities where cancer diagnosis and treatment occurs. This would involve all hospitals in Ontario that provide cancer surgery, radiation or systemic treatment;
- Set the standard on how often stage information is collected. Because stage changes during the lifetime of the disease, standard reporting points must be defined to ensure clinical stage information is collected consistently across the province; and
- Establish a common method of data collection and standard definitions to support consistent data quality regardless of how the information is actually entered into the system (e.g., transcription, physician entry, coded abstracts, etc).

Capturing clinical stage information will:

- Support evidence-based care and improve patient safety;
- Facilitate monitoring of outcomes and targeting areas for improvement;
- Increase early detection of cancer through screening;
- Improve system planning; and
- Enhance infrastructure for cancer research.

SURGICAL ACTIVITY TRACKING

Approximately 80% of cancer patients undergo an invasive intervention or surgical procedure for diagnosis or treatment of cancer. About 22% of these interventions or surgical procedures are done in the eight host hospitals associated with CCO. In addition, relatively few surgeons have practices that consist mainly or solely of cancer surgery. Rather, they tend to operate on a variety of conditions within their specialty.

There is strong evidence that it is important from a quality perspective to track surgical volumes by physicians and report back outcomes compared with provincial and regional peer groups. Some studies show widely varying clinical outcomes in different centres across the province for cancer surgery. The best-known example is surgery of the pancreas where post-operative mortality rates were shown to vary by a factor of ten. A strong correlation exists between poor outcomes and small volumes.

To improve access to and quality of surgical procedures, a surgical activity tracking mechanism needs to be developed which includes:

- Analytical function – CIHI collects good data on surgical procedures. With proper analysis, this data could be used to develop performance benchmarks and establish outcome measures;
- Linking ability – comprehensive performance data can be achieved by linking CIHI procedural codes to stage, PIMS and wait list information; and
- Reporting function – consistent data enables reliable reporting back to physicians and administrators on care performance measures (like quality and access) relative to peers.

Developing a system to collect information about cancer surgery and link this information to clinical practice guidelines will be a tremendous step towards improving the quality of cancer surgery. The implementation of a surgical activity tracking system will:

- Improve access management for cancer care services;
- Monitor outcomes and target areas for quality improvement;
- Improve system planning; and
- Enhance infrastructure for cancer research.

SYSTEMIC THERAPY MANAGEMENT SYSTEM

Comprehensive data on systemic therapy is difficult to obtain since it is provided in regional cancer centres and in other hospitals, only some of which are affiliated with CCO. Although CCO and Princess Margaret Hospital collect detailed data on systemic therapy, there is limited provincial information on such things as diagnosis, location of treatment, compliance with best practice guidelines, outcomes, stage and costs. Furthermore, CIHI reporting requirements in Ontario do not require abstracts for outpatient systemic therapy.

All care programs should be designed to help care givers prevent clinical errors. Rather than assigning blame to a particular caregiver, the emphasis should be placed on improving the clinical process that allowed such an error to occur. In the case of drug therapy ordering, there is strong evidence to suggest that computerized physician order entry of drug orders can significantly reduce error rates. This is especially true if the drug order entry system includes clinical decision support for physicians with suggestions on how to improve ordering practices that are consistent with evidence-based guidelines.

There are opportunities to improve the quality of systemic therapy treatment by developing a comprehensive systemic therapy management system with the following functions:

- Computerized Physician Order Entry *(CPOE) to reduce error and facilitate better data collection on the use of systemic therapy throughout the province; and*
- *Clinical Decision Support* system to provide physicians with suggestions on how to improve ordering practices that are consistent with evidence-based guidelines.

It is recommended that a common province-wide systemic management system be implemented to achieve computerized physician order entry for chemotherapy across the province. The system will be linked to other information sources, like staging and PIMS, to support measuring of outcomes and implementing of quality improvement programs.

A comprehensive systemic therapy management system will:

- Support evidence based care and improve patient safety;
- *Facilitate monitoring of outcomes and targeting areas for improvement;*
- Improve system planning; and
- Enhance infrastructure for cancer research.

RADIATION THERAPY MANAGEMENT SYSTEM

Cancer centres require specialized systems for managing radiation therapy services. Standardizing on a common radiation system would result in economies of scale that include cost efficiencies, consolidated reporting opportunities and improved quality of care. Currently there are two classes of radiation systems: standalone radiation therapy management systems and radiation systems that are integrated into broader oncology information systems.

There are opportunities to improve radiation therapy management by:

- Centrally consolidating radiation specific information from all cancer centres and Princess Margaret Hospital;
- Integrating radiation systems with host hospital systems (e.g. laboratory, PACS, pharmacy) to improve care delivery; and
- Integrating radiation centre information across the province to support system planning and comprehensive outcome analysis.

To leverage radiation systems for improved care and increased efficiency, a standardized system for radiation services must be selected. Options include:

- CCO provides and manages a single vendor solution for all Ontario centres;
- CCO permits each RCC/Hospital to select and implement its own specialized system that conforms to CCO defined functionality and reporting specifications; and
- CCO selects a single vendor for adoption by all centres.

The radiation therapy management system will require:

- Integrated radiation information by capturing data feeds from all radiation centres into D-TRACC;
- Common definitions of service units required to support analysis and comparison; and
- Consistent capture of staging information.

A key challenge to implementing a radiation therapy management system is to obtain consensus agreement on a single system to use. Currently, centres are divided on whether to use a standalone radiation therapy management system or a broader, integrated oncology information system.

Development of a radiation therapy management system will:

- Improve access management for cancer care services;
- Support integration of service delivery;
- Support evidence based care and improve patient safety;
- Facilitate monitoring of outcomes and targeting areas for improvement;
- Improve system planning; and
- Enhance infrastructure for cancer research.

REGIONAL ELECTRONIC HEALTH RECORD INITIATIVES

Currently, the majority of cancer clinical activity in Ontario is supported by paper and manual processes. There is limited access to information systems for direct patient care, clinical systems are not integrated and there is a lack of clinical decision support to guide practice. Significant delays in clinical care occur when time is taken to look for and transfer paper-based information, and significant costs are incurred with redundant processes and repeated tests. All of these issues impact on the quality of patient care.

An integrated Electronic Health Record (EHR) that links the broad range of clinical cancer care services provided in a region does not exist in most parts of the province. A comprehensive EHR would integrate disparate systems and processes, and would be used to coordinate cancer care, facilitate referrals and support communication between clinicians. The EHR will be regional, rather than provincial, and based in hospitals. Hence, there will not be a CCO-based EHR or a cancer specific EHR.

Various factors support the need for a regional EHR rather than a provincial or disease specific EHR:

- Different vendors across the province increase the difficulty of implementing a provincial EHR;
- The EHR should be patient-centric and not based on a single disease. Most of the care provided to an individual patient is likely to occur in the same region; and
- All clinical information on each patient should be electronic, and not limited to cancer information.

The following opportunities would support implementation of a regional EHR:

- Leverage host hospital EHR initiatives by making PACS, laboratory, and physician order entry functionality available to regional cancer care providers;
- Develop and implement data standards and integration strategies across CCO, PMH and hospitals so clinicians can access clinical data on patients referred from other centres;
- Increase patient record content that is available electronically;
- Develop and deploy EHRs that can use clinical practice guidelines and workflows (e.g., physician order entry, results reporting, scheduling); and
- Leverage point of care clinical decision support by integrating guidelines with the EHR.

A key challenge to the development of regional EHRs is each hospital's willingness and ability to develop an effective EHR. Developing an EHR requires significant skill-sets, funding and a dedication to integration. While many hospitals aspire to develop such a tool, many are at different points on the implementation timeline. As a result, regional EHRs will develop at different rates throughout the province.

Development of regional EHRs will:

- Improve access management for cancer care services;
- Support integration of service delivery;
- Support evidence based care and improve patient safety; and
- Facilitate monitoring of outcomes and targeting areas for improvement.

CLINICAL TRIALS ENROLLMENT AND MANAGEMENT

Clinical trials are a cornerstone to ongoing improvement of care. Currently, enrollment in clinical trials is a complex undertaking due to the number of trials conducted across the province, the variety of sponsors and the relative independence of each trial. Furthermore, since appropriate software is not available, many organizations have developed their own standalone products to support trials. These products do not integrate with each other or with other relevant systems.

A comprehensive clinical trials management system would support effective eligibility screening and tracking of patients by:

- Providing a comprehensive list of clinical trials that are open and available across the province;
- Identifying patient eligibility requirements through trial summaries;
- Linking to national or international trial databases;
- Providing a list of centres running trials;
- Documenting all required findings from the clinical trial; and
- Supporting analysis and reporting of findings.

To be successful, the clinical trial system must identify and keep track of patients who are eligible for clinical trials. Once a patient has been diagnosed, physicians must be able to determine easily and quickly the eligibility of the patient. Time is of the essence since changes to medication or treatment may render a patient ineligible for a trial. In addition to the research and treatment benefits derived from trials, improved ability to accurately record patient participation in clinical trials together with treatment costs will allow greater recovery of costs from trial sponsors.

The following opportunities would maximize clinical trial enrollment and are consistent with the needs and objectives of the Ontario Cancer Research Network:

- Effectively document and communicate clinical trial requirements to physicians and clinicians that outline when a trial is available and patient eligibility requirements;
- Develop a single or standardized clinical trial management system that identifies relevant trials to potential candidates and also supports the data collection requirements of the trial;
- Develop linkages to relevant hospital information systems for timely identification of potential candidates and to support clinical trials accruals through electronic screening, reminders and education support;
- Promote awareness and understanding of relevant clinical trials among physicians and clinicians; and
- Reduce manual, paper-driven processes for clinical trials through electronic-based data collection.

Clinical trials enrollment and management will:

- Support evidence based care and improve patient safety;
- Facilitate monitoring of outcomes and targeting areas for improvement; and
- Enhance infrastructure for cancer research.

CLINICAL DATABASES TO SUPPORT TUMOUR BANKING

Genetic information is emerging as a key component necessary for making treatment decisions tailored to the characteristics of individual patients. To establish the relationships between tissue genotype and optimal therapy, research efforts are being directed increasingly at studying the specific genetic determinants that control the aggressiveness of certain tumours in patients, their likely clinical course, sensitivity to radiotherapy, or susceptibility to drug treatment. Ultimately, it is hoped that a genetic profile can be obtained for each patient's tumour cells so that therapy can be individualized.

To achieve this objective, the Ontario Cancer Research Network has launched a major initiative to develop a virtual tumour bank that enrolls 50% of all newly diagnosed cancer patients each year.
Linkage of a patient's genetic bio-file with clinical record information is the key to understanding the genetic determinants of clinical course of disease and its response to therapy. Given the large number of genes in the human genome and the multifactorial nature of genetic expression, it takes large numbers of patients in a single database to correlate genotype with clinical behaviour.

Ontario has a unique opportunity to establish a single standard data structure to capture tumour information for the entire cancer population. Provincial coordination is essential to develop this single database and the information infrastructure to support it. Once the relationships between genotype and clinical behaviour are understood, clinicians will need access to the patient's genetic bio-file to optimize their treatment program. Enabling a link between the tumour bank and clinical databases is necessary for translation of research results into clinical practice.

Opportunities to develop an integrated database architecture include:

- Linking genetic profiles and tissues in a tumour bank with a clinical database summarizing the patient's clinical course;
- Incorporating staging, treatments received, pathology findings and outcome elements;
- Receiving patient clinical data from originating systems in treatment centres before and after tissue has been banked; and
- Coordinating provincially and addressing the requirements of both the research community and patient care.

A clinical database to support tumour banking will:

- Enhance infrastructure for cancer research.

PROVINCIAL HUMAN RESOURCES PLANNING SYSTEM

The delivery of cancer services will be affected by the shortage of health care professionals plaguing the broader health care system. In particular, cancer care is experiencing a shortage of nurses, radiation therapists, oncologists, physicists, anesthetists and pathologists that is expected to worsen in coming years. Detailed inter-institution information is not available to project future supply of specialized clinical professionals as it is affected by training programs, retirements, immigration, etc. To ensure effective human resource planning, demand and supply of services must be forecast to allow system managers to project future human resource needs.

A human resource tracking system is required to:

- Track and understand resources dedicated to providing cancer care to identify future needs and project future supply of clinical professionals;

- Provide data for the development of an overarching provincial strategy to support the training, recruitment and retention of a sufficient number of appropriately trained professionals to provide cancer services; and

- Identify potential gaps in the system before they become critical, while focusing on strategies to improve retention and productivity in key areas.

For implementation of a provincial human resource system to facilitate better planning, it must be recognized that many factors influencing human resources are beyond the control of any single provider. However, with effective cooperation, a human resource system will:

- Improve access management for cancer care services; and
- Improve system planning.

SCREENING TRACKING SYSTEM

Development of a provincial screening strategy is difficult in the absence of sufficient comprehensive screening information. This information is required to develop organized screening programs that will detect cancer earlier, and thereby decrease acuity, prevent illness, lower system costs and improve patient outcomes. Currently, Ontarians are not always informed of the availability of screening services. As well, ad-hoc screening efforts are neither centrally reported nor standardized. Screening programs must be continually assessed and improved to ensure all Ontarians, who meet guidelines, have access to timely screens.

A screening tracking system will collect screening information from all centres providing screening services in Ontario, report participation rates for the populations targeted and identify priority areas that require increased attention to improve participation. A comprehensive approach to screening monitoring includes quality testing, appropriate follow up, routine reminders about the next required screening test and an evaluation of outcomes. Evidence-based practice will be promoted through the dissemination of screening guidelines. Quality data will support a provincial screening strategy, ongoing strategic planning and development of new programs.

Implementation of a provincial screening tracking system requires significant cooperation of the large number of primary physicians and others providing screening services. Agreements must be reached to ensure standardized data collection.
A screening coverage monitoring system will:

- Improve access management for cancer care services;
- Support integration of service delivery;
- Support evidence based care;
- Facilitate monitoring of outcomes and targeting areas for improvement;
- Increase early detection of cancer through screening; and
- Improve system planning.

GUIDELINE USE TRACKING SYSTEM

Practice that is consistent with guidelines results in high quality care. CCO's Program in Evidence Based Care (PEBC) supports, develops, disseminates and regularly evaluates guidelines. Currently, it is difficult to determine the degree to which guidelines are applied across the province and the extent to which there is consistent high quality practice. Tracking the availability and use of guidelines would be particularly useful in regions where there are low to medium volumes of cancer treatment and less likelihood that physicians are exposed to evidence-based guidelines.

A guideline use tracking system would track the use of guidelines, monitor the consistency in practice with evidence and promote the development of clinical decision support tools to support the dissemination and use of guidelines. If practice is inconsistent with guidelines, the system could document why guidelines are not being applied. This may promote new knowledge about the need for different treatments. Guidelines would be constantly reviewed, updated and new guidelines developed based on the linkage between guideline use, outcome information and staging.

The creation of a guideline use tracking system requires extensive system modification and behavioural change. For example, systems would need to be integrated with clinical decision support mechanisms to alert physicians of up-to-date guidelines. Physicians would also need education about the guidelines and their relative success for improving quality outcomes for patients. Systems can suggest guidelines that are consistent with evidence but cannot force the adoption of guidelines.

A guideline use tracking system will:

- Support evidence-based care and improve patient safety;
- Improve access management for cancer care services;
- Support integration of service delivery; and
- Facilitate monitoring of outcomes and targeting areas for improvement.

ENHANCEMENT OF THE ONTARIO CANCER REGISTRY

The Ontario Cancer Registry (OCR) is a computerized database of information tracking all incidence and mortality of cancer cases in Ontario. All new cases of cancer are registered, except non-melanoma skin cancer. Between 1964 and 1999, 1,132,683 incident cases were registered. The OCR is an invaluable resource for conducting epidemiological studies, evaluating the efficacy of screening programs, and recently has been used in health care utilization studies.

Typically, all of the uses of the OCR described above use patient data that is passively collected. Due to delays in receiving complete patient information, it has not been possible to obtain real time data to assist in active clinical decision-making. It is hoped that upgrades to the OCR and improvements in data collection will enable closer to real time data to be received. One of the main drivers behind enhancing the OCR is to improve clinical decision-making, including the ability to identify patients eligible for clinical trials before treatment has begun.

Opportunities to enhance the Ontario Cancer Registry include:

- Include real-time or close to real-time entry of cancer specific patient information into the OCR. This might involve electronic links to other healthcare information systems which feed into the OCR;
- Satisfy privacy legislation or modify data collection to enable the utilization of patient-specific data in the OCR for clinical and research purposes;
- Implement a Master Patient Index which ensures high fidelity linkage of clinical data coming from different sources; and
- Improve data quality and database matching mechanisms to reduce errors and duplication of entries and allow for more active use of the OCR.

Enhancements to the OCR will:

- Facilitate monitoring of outcomes and targeting areas for improvement;
- Increase early detection of cancer through screening;
- Improve system planning; and
- Enhance infrastructure for cancer research.

Appendix 12: Glossary

Cancer Quality Council of Ontario (CQCO)
In September 2002, the Minister of Health and Long-Term Care announced the establishment of the Cancer Quality Council of Ontario (CQCO) to "monitor, assess and improve clinical and health system performance of all cancer services in Ontario. The CQCO requires system level data to perform its function.

Cancer Services Implementation Committee
The Cancer Services Implementation Committee was struck in response to public concerns about waiting lists for radiation therapy and the ability of the current system to meet the growing need for cancer services of all kinds. The focus of the Committee was to recommend ways to improve the integration of cancer services at the local and regional levels, the quality of patient care, and the productivity and efficiency in the cancer service component of the Ontario health system.

Cardiac Care Network of Ontario (CCN)
The Cardiac Care Network of Ontario is an advisory body to the Ontario Ministry of Health and Long-Term Care dedicated to improving quality, efficiency, access and equity in the delivery of cardiac services in the Canadian province of Ontario.

CIHI
The Canadian Institute for Health Information (CIHI) is an independent, pan-Canadian, not-for-profit organization working to improve the health of Canadians and the health care system by providing quality, reliable and timely health information.

Clinical Decision Support (CDS)
Clinical decision support aids clinicians in decision making by matching individual patient characteristics to computerized knowledge bases for the purpose of generating patient-specific assessments or recommendations. This tool allows physicians to deliver a standardized practice and evidence based care, which results in better patient outcomes.

Computerized Physician Order Entry (CPOE)
Computerized Physician Order Entry is an online computer application that accepts physician orders electronically. It replaces the physician writing orders on an order sheet or prescription pad.

Data Tracking, Referral and Analysis of Capacity for Cancer (D-TRACC)
DTRACC is intended to provide consistent management information on cancer treatment activity,quality and accessibility.

EHR – Electronic Health Record
The electronic health record is a patient record which tracks a patient through the continuum of care, from birth to death. This patient record accounts for all patient interactions with the health care system.

EPR - Electronic Patient Record
The electronic patient record is a patient record which tracks a patient through the care received within an organization or health care facility. The scope of this record is smaller than that of the EHR.

HL7
Health Level 7 is a messaging protocol designed to facilitate communication and interoperability between divergent information systems.

ICES
The Institute for Clinical Evaluative Sciences is an independent, non-profit organization with a mandate to conduct health services research that contributes to the effectiveness, quality, equity and efficiency of health care in Ontario.

Integrated Cancer Programs (ICP)
An Integrated Cancer Program is a program that will be operated by the host hospital with funding from CCO. The scope of an ICP will encompass referrals, diagnostic procedures, all aspects of care, as well as discharge and follow-up.

Interface Engine
A 'bridge' which allows for the flow of information between disparate systems.

Modality
A therapeutic method or agent, such as surgery or chemotherapy that involves the physical treatment of a disorder.

MPI
A master patient index is a repository which contains a unique identifier for each patient. The unique identifier is essential in identifying patients across the health care system, regardless of where it was delivered.

Ontario Cancer Registry(OCR)
The Ontario Cancer Registry (OCR) is a computerized database of information. The purpose of the database is to track all of the incidences and mortality of cancer cases in Ontario.

Ontario Cancer Research Network (OCRN)
The Ontario Cancer Research Network is a four-year, $100 million initiative of the Ministry of Enterprise, Opportunity and Innovation of the Government of Ontario designed to fund infrastructure and innovative programs in translational and clinical research, information technology and data management that will enhance cancer treatment in Ontario.

OPIS 2000
A graphical user interface for the OPIS database.

Organizational Integration
Organization integration is stronger collaborative efforts by host hospitals and regional cancer centres which result in common systems and reduce the organizations duplication of effort.

PACS
Picture archive communnications system is a digital imaging system that stores and distributes digital images from CT, MRI, Ultrasound and Xray scans.

Palliative
The relieving or soothing of symptoms of a disease or disorder without effecting a cure.

Program in Evidence-Based Care (PEBC)
The Program in Evidence-Based Care (PEBC) uses research results to influence practice by developing evidence-based clinical practice guidelines.

RCC – Regional Cancer Centre
A regional cancer centre is cancer centre located in one of eight regions (Hamilton, Kingston, London, Thunder Bay, Sudbury, Ottawa, Windsor, Toronto). Each regional cancer centre is responsible for the governance of cancer services in their respective region.

Screening
Primary care services which are conducted in hopes to detect cancer at its onset so as to allow for early intervention and a greater chance of successful cancer treatment.

Supportive
Supportive care helps meet the physical, emotional and spiritual needs of people who have been challenged by cancer.

Systemic Therapy
Systemic therapy is administered orally or directly into the bloodstream to reach cancer cells that may have spread beyond the breast. Chemotherapy, hormone therapy, and immunotherapy are systemic therapies.